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ABSTRACT

Presented are a conference summary and 15 papers on the present and future service needs of deaf-blind (rubella) children and their parents. The conference summary contains recommendations for future activities; major points of agreement among conference members; synopsis of the papers presented; a review of discussion by conference participants; suggestions made by regional coordinators and other conference observers; and a chart to show hours per week per child needed for education, service, or training. Papers presented at the conference are grouped according to the following major themes: identifying and servicing the deaf-blind, current services and plans for expansion, characteristics of the population, legal aspects and model programs. Discussed in the papers are such topics as fragmentation of present service delivery programs; vocational training and research or sensory aids; teacher recruitment and training; the potential for development of skills in middle trainable, upper trainable, and middle educable deaf-blind children; legal precedents related to the developmental model of disability and the principle of normalization; and model programs for research, administration, evaluation, education, or treatment of the handicapped. (LH)

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1980 IS NOW

A Conference on the Future of Deaf-Blind Children

Edited by Carl E. Sherrick

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Foreword

Edgar L. Lowell
Administrator
John Tracy Clinic

The rubella epidemic of 1934-65 increased the number of deaf-blind children in the United States to more than 5,000. By 1980 these children will be adolescents. Their individual and social needs will be different and their service needs will be changing.

The conference, 1980 IS NOW, was an expression of our concern about the future needs of these deaf-blind children. And the child is not alone in his needs. He has parents whose anxiety is growing. They worry about where he can go, what he can do, and who will care for him. They wonder what possibilities the future holds for their child as a person, and for themselves. As we try to foresee these needs and make plans to satisfy them, it is essential that these humanistic concerns influence our decisions. In our attempt to satisfy their obvious physical requirements, we must not forget the equally important needs that each one of them has as a person.

In order to meet their individual needs, we had hoped to present an overview of the needs of the deaf-blind population as a whole. The purpose of 1980 IS NOW was to serve as a stimulus to prior planning to accommodate the maturing individuals within the deaf-blind population. We planned to make estimates of the number of people requiring service in 1980 and their geographical distribution. Not all deaf-blind children will benefit from the same services and facilities, so we planned to select and describe a number of service programs that would serve as national models. We also needed to consider the effect of recent changes in laws relating to the handicapped and their potential effect on the future of the deaf-blind child. By exploring these diverse areas, we hoped to establish a framework within which we could organize our resources, evaluate our priorities, and determine what facilities and personnel were required.

Without such a framework, long-range planning is not possible. Without long-range planning, programs become ineffective. Services are duplicated or omitted. Needs are not anticipated, so funds are not available. Without long-range planning, there is a loss of opportunity for the deaf-blind individual.

In the clarity of hindsight, it appears our goals may have been too ambitious. We did not complete all of our objectives. In part, this may have been because of the many different points of view represented by the participants. Or, it may have been that our preoccupations with current service needs made it difficult to speculate about tomorrow's needs.

The participants were selected from a broad cross section of agencies serving the deaf-blind: educational, legal, social, vocational, public, and private. All participants prepared papers that were circulated prior to the meeting. These papers and a summary of the discussions are the foundation of this report. Regional Deaf-Blind Center Coordinators participated in the discussion and their observations made a substantial contribution.

The discussions were stimulating and served to emphasize the complexity of our task. A beginning was made in terms of a few specific recommendations for future action, but more importantly, the group was sensitized to the need for future planning.

We hope the conclusions and recommendations coming from the 1980 IS NOW conference will create an impetus for the long-range planning that is needed to develop effective programs and opportunities for every deaf-blind person.

Preface

In searching for a term that would encapsulate the good intentions of the medical, legal, research, and teaching professions to improve the quality of life of the rubella children, I found the word "euthenics" in ***Webster's Third New International Dictionary, Unabridged.*** The definition follows: ". . . a science that deals with developing human well-being and efficient functioning through improvement of environmental conditions."

It is doubtful that "euthenics" will catch on, associated as it is with its neighbors, eugenics and euthanasia, both of which have in the past aroused religious and/or racial fears. Moreover, euthenics is a very broad term that covers the physically handicapped, the emotionally disturbed, and the retarded, as well as the victims of social and economic privation. Having mentioned all these groups, however, perhaps we should examine their plight to determine what it is they share. Their common affliction, one may say, is not their physical status, or emotional status, or anything about their individual attributes. It is that they exist within a society that is itself at times and in places handicapped, disturbed, retarded, or deprived. It would be more generous, and more optimistic, to say that we are an immature society that has only begun to affirm its obligation to all its citizens in a regulated and organized manner.

I am sure it is the hope of all who attend this conference that one of its major outcomes will be the recruitment and organization of agencies, individuals, and institutions to provide the necessary distribution of physical and human resources needed to surround the rubella children with the best world possible. In some small measure the regard of our society for itself may thus be elevated.

C. E. Sherrick
Princeton, New Jersey
July 24, 1974

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To Ms. Carole Frouin, Coordinator of the Conference, whose administrative and editorial skills are surpassed only by her capacity for hard work and attention to the smallest detail, the deepest personal indebtedness of the Chairman and the Editor is acknowledged.

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Summary of the Conference

Final Recommendations of the Conference

The significance of any conference rests upon its ability and willingness to specify directions for future activities on the part of its sponsors and participants. Five such major recommendations clearly emerged from the papers and discussions of the present conference:

1. The planning efforts of all agencies of the federal, state and local governments, as they relate to the problems of services to the deaf-blind, must be concerted to avoid duplication and inefficiency, and must be initiated within a very short time if realistic goals for this maturing population are to be met by 1980.
2. The more accurate definitions of the terms "deaf-blind" or "rubella child" among others, await the compilation and processing of data on numbers of such multihandicapped individuals as well as on evaluative procedures and diagnostic results. The information forthcoming from the study by the Management Analysis Center may provide better perspectives on current procedures for the acquisition and analysis of such data. In light of this information any necessary revisions or improvements of data-gathering practices are strongly urged.
3. The stress laid by various authorities on the need for a continuum of services from childhood through adolescence and adulthood is reinforced by the present conference. In repeating this call for uninterrupted support of development of the handicapped person, the importance of close inter-agency cooperation, e.g., between the Bureau of Education for the Handicapped and Social and Rehabilitation Services, cannot be overemphasized.
4. Whereas there are on record a number of current and projected programs for training personnel involved in services to the handicapped, it is not clear that the distribution of skills and levels of competence match the requirements of the groups to be serviced. Accordingly, it is recommended that a working conference with a specific agenda and papers be convened as soon as possible to identify and formulate those areas of competence needed for dealing with the handicapped population of 1980, ranging from para-professional personnel through highly trained specialists.
5. Efforts should be made to fund the development of a spectrum of model living and working styles for the deaf-blind, ranging from sheltered satellite home arrangements with sheltered employment sites, to foster homes in normal communities. The impact of the model programs on the surrounding communities should be gauged if possible. A major part of these projects must be the careful evaluation of the social, intellectual, and vocational progress and achievement of the individual, as well as the evaluation and documentation of the program as a whole.

These should not be taken as the sole and unanimous set of opinions to emerge from the conference. In each paper are clear and definite arguments for particular courses of action, along with, in some cases, results achieved by action already initiated.

Whatever the source, each recommendation shares the attribute of urgency. Reasoned and responsible action by both sponsors and participants is needed soon if significant and beneficial changes are to take place in the world of the deaf-blind child.

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Summary of the Conference

Synopsis

What follows is a condensation of the major features of the conference, including papers presented, the discussions that ensued among the participants and the reactions of observers.

There were seven major points of agreement among members of the conference, and these may serve to characterize it in brief:

1. The purpose of the 1980 IS NOW conference was to bring together individuals who are presently involved as professional personnel in programs for direct aid to the handicapped, or who are in administrative roles relating to such aid, from various governmental and private organizations. The major problem of the conference was to determine what must be done to arrange for the delivery of adequate service to the large number of handicapped children produced by the rubella epidemic of 1964-65, who in 1980 will be approaching adulthood. Present facilities for the group, estimated to number 5,000 or more countrywide, seem to be wholly inadequate to meet its needs for therapy, education, counseling and training. In only six years, nevertheless, the group will have attained near maturity. Unless careful plans are laid to expand, coordinate and refine present programs for the seriously handicapped children and adults of this country, the consequences may be medically, legally, and socially disastrous.
2. Time is of the essence in the actualization of whatever plans emerge from the various organizations concerned with programs for improving the wellbeing of the handicapped. The very title of the conference is intended to convey the urgency of the problem and its solutions.
3. Vastly improved communication and coordination among the organizations and agencies at the federal, state and local government levels, as well as in the private sector, are required to improve the efficiency and equitable distribution of diagnostic, evaluative, therapeutic, educational, and social services to the rubella victims, and to other multihandicapped children and adults.
4. Present estimates of the number of multihandicapped children may very likely be revised upward, as expanded and better-integrated programs in detection and treatment are developed.
5. The expansion of institutional facilities, at least in their traditional sense, is not a just solution to the problems resulting from the appearance of a group of multihandicapped children such as was produced by the rubella epidemic. Indeed, in the long run, the best interests of society, from any standpoint, are not served by traditional institutionalized facilities for such individuals. Among alternative models for environmental care are the "satellite homes" model and its variants.
6. In connection with (5) above, it is likely that public school systems may, in some regions, be required to provide more special facilities and personnel than they do now, without regard for the degree of handicap or the costs involved.
7. High on the list of priorities for action is the problem of tapping available human resources for professional positions in all phases of the program for the multihandicapped, including research, diagnosis and evaluation therapy, education, vocational rehabilitation, and social service. The expansion of personnel training programs for new trainees, and for occupational conversion of persons previously trained in related fields, is a primary and pressing need for the success of the programs discussed in the conference.

Summary of the Papers

Each of the papers circulated prior to the conference or presented during the sessions stands as a unique contribution. Nonetheless, it is possible for purposes of the summary to arrange them according to five major themes. It should be understood that in so doing there may be some distortion of one or more of the papers. Nothing can replace reading the original text, of course.

Under some of the themes presented below will be found only one paper, whereas in others the same paper will be cited more than once. This results, again, from the individual character of the papers and the multiple authorship. The editor apologizes to those authors whose viewpoints may have been distorted, or overlooked, in the process of condensing the information they presented. Wherever doubt or confusion may arise, the reader is again urged to consult the original paper for clarification.

Identifying and Servicing the Deaf-Blind

Papers dealing with the problems of identifying and servicing the deaf-blind population as it is presently estimated: Three papers make up this category: Brewer and Kakalik, Dantona, and Nash *(Silent Children)*. These authors set the stage for discussion of the magnitude of the problem facing professionals in the field of service to the handicapped.

Brewer and Kakalik conclude, on the basis of a statistical survey of service recipients and of responses from service agencies, that present service delivery programs are seriously fragmented among several organizations, and integration of effort is badly needed for existing as well as for proposed programs.

Dantona provides a picture of the present and projected service delivery from the standpoint of the Regional Centers for the Deaf-Blind, presenting a brief demographic analysis of the current placement system, and an analysis by age level of present and anticipated deaf-blind cases.

Nash's paper is interpretative and projective in his statements concerning the quality of service available to the handicapped. He suggests several sources of present and expected difficulties in programs for diagnosis, treatment, and education of the multihandicapped.

Current Services and Plans for Expansion

Papers dealing with currently available services, special facilities, and plans for expansion, including research and teaching or personnel training programs: Under this rubric may be placed six papers: Dantona, Herman, MacFarland, Nash *(The Georgia Program for the Deaf-Blind)*, Salmon and Spar, and Taylor.

Dantona describes the several current activities of the Regional Centers for the Deaf-Blind, and places dollar amounts on funding for three fiscal years. A broad range of activities for the present and coming fiscal years is listed, from direct educational programs to parental counseling services.

Herman describes the position of the Bureau of Education for the Handicapped as at a decision point. He expects that input from conferences like the present one, and from studies by Management Analysis Center (MAC), will in the next few months permit reaching intelligent decisions concerning the expansion of funding of programs for the deaf-blind, and commitment of resources to them, providing a continuum of services from birth to maturity. Implicit in this author's suggestion of the possibility of new or greater commitments to programs is the admonition that success hinges on the well-reasoned analysis of needs and design of programs for service.

MacFarland presents a brief history of the establishment of the National Center for Deaf-Blind Youths and Adults, characterizing its present contribution to rehabilitation as threefold:

1. vocational training of deaf-blind of 18 years or older,
2. training of service personnel from other organizations, and
3. research on sensory aids and training devices or methods for use by the deaf-blind.

The hope is stated that the close coordination and integration of the National Center with Rehabilitation Service Centers in all parts of the country will make possible the best available service to clients in or near their home communities.

Nash *(The Georgia Program for the Deaf-Blind)* in his second paper provides a description of current services in the state of Georgia for the multihandicapped child and details the development of the program from its beginning in 1969 to the present, especially the coordination of activities among existing state institutions and agencies along with the expansion or initiation of services of other agencies.

Salmon and Spar present a detailed account of services offered by the National Center for Deaf-Blind Youths and Adults, as well as adducing data on the number of deaf-blind persons trained and placed successfully by it. In discussing the present and projected role of the National Center in the expansion of services to the deaf-blind, two notes of caution are sounded:

1. the definition of deaf-blindness must be thoughtfully made, and identifications of clients performed carefully, and
2. the associated problem of population estimation through statistical surveys must be conservatively gauged, to avoid panicky administrative actions.

The lessons learned by the National Center should prove to some extent to be transferable to the present problems of rubella children.

Taylor deals with the recruitment and training of teachers for work in special education programs for the deaf-blind in public school, institutional, or private settings. Current status of the college training programs is described, and the need for conversion of teachers in other areas to work with the multihandicapped is underscored. Although new programs will not be so difficult to begin since the BEH has learned from those already under way, the direction of effort and skills required for training maturing youth demands some changes of strategy in program design.

Characteristics of the Population

Papers dealing with the character of the population of rubella children, and the problems expected in attempting to improve the quality of their lives: Smith's is the sole paper of this group. The author divides the population into three levels, and assigns estimates of their share to the total:

1. Middle trainable and below, 60 to 75 percent, are those whose best prognosis is to achieve levels of personal care and physical control, with a minimum capability for social interaction. Many will not achieve these levels.
2. Upper trainable through lower educable, 15 to 25 percent, are those who can achieve personal independence, and, with training, acquire useful vocational skills, or some academic education, to lead semi-independent lives.
3. Middle educable and above, 5 to 10 percent, are those deaf-blind who may not even be rubella children, and who, though sensorily afflicted, can be trained and educated to very high levels of proficiency, sufficient to lead independent lives in unsheltered employment and living conditions.

There is throughout the paper stress on the conviction that a child thought to be in the lowest category may surprise the prognosticator and rise to a high level of performance.

A discussion of appropriate facilities for the various levels is presented, recommending cottage-style small-group accommodations for the institutionalized child at the lower levels, and a similar but more open arrangement for middle level children, including foster homes. For the educable, foster home programs would be desirable to bring the able child into contact with the undistorted world.

Smith states the "handicapped society" principle, which emphasizes the need to re-educate the public concerning the rights to education and training of the special minority group of handicapped persons of all ages.

Legal Aspects

Papers dealing with the legal aspects of the definition, diagnosis, evaluation, treatment, education, and rehabilitation or support of the handicapped: Laski states the legal philosophy regarding the treatment of the handicapped by society. This author cites several cases in law that effectively establish precedents for the probable judgments for the handicapped, if suits are entered. Educational, medical and legal aid for mentally retarded children have been gained by suit, and similar outcomes may be predicted for suits on behalf of multihandicapped children.

Two major socio-legal premises are stated:

1. *The Developmental Model of Disability,* which views any individual as ultimately the product of interactions between his person and his environment, stressing equally the character of the environment and that of the person.
2. *The Principle of Normalization* requires simply that the life-style of the handicapped individual be as much like that of the normal as possible.

Under these premises, the law may hold professionals who deal with the handicapped responsible for any deviation from optimal and prompt application of service to the child.

Model Programs

Papers that describe model programs for research, admintration, evaluation, education, or treatment of the handicapped: Five papers are comprised by this topic, which was to become an important part of the discussion. Hammer, Martin and Herman, and Nash *(Georgia Program)* present models for service delivery. Lowell proposes a model for research strategies, and Rieger details a model therapeutic program currently under test.

Hammer, in an analysis of the administrative problems and priorities involved in program planning for expanded and innovative services for rubella children, asks specific questions concerning the roles of federal, state, and local governments, the needs for modifying programs according to age requirements, the sources of funding, its probable duration, and the role of research in developing programs. The author offers a pictorial model to suggest the administrative relationship of the BEH, regional centers, state agencies, and a proposed *Case Manager, i.e., an* individual or group who guides, advocates, and evaluates the progress of clients through the various services available to them.

Lowell outlines the problems of effective research in educational or clinical settings, and delineates two major shortcomings in much of the previous research. One is the lack of clear-cut and objective evaluation of the effects of experimental treatment, and the second is the ineffectiveness of dissemination of the research to appropriate and interested readers. To eliminate faults, the author recommends division of the service, evaluation and documentation functions among three distinct teams. To coordinate the functions for proper and efficient action, a project monitor separately appointed (perhaps from another, independent organization) could oversee the entire program.

The policy paper by Martin and Herman poses the current problem of multihandicapped children, especially the poor, in brief: current service activities are not available to all handicapped children on an equal basis, owing to geographic distribution and disparate levels of program development among states or local school districts. The authors outline activities needing the most support, and propose seven possible steps to the solution of problems, within the federal responsibilities, including establishment of minimal conditions to which states subscribe to receive federal support, development of diagnostic teams for early identification of clients, revision of college curricula for teacher training to improve the average teacher's understanding of needs of the handicapped, subsidization of retraining of teachers for the handicapped, and cooperation with state employment agencies to develop better vocational programs that result in meaningful employment for the multihandicapped individual.

Nash's paper on the *Georgia Program for the Deaf-Blind* describes eight objectives for the future of the state program. These are intended to increase the capacities of the program for identification, diagnosis, evaluation, and education of the deaf-blind, and extend age limits up to 16 years for clients. This portion of the paper provides a possible model for action by states and the federal government.

Rieger emphasizes the inadequacy of institutional environments for providing the kind of parental and peer figures that the growing child needs to mature emotionally and socially. The author's solution for disturbed children, was the development of "satellite homes", domiciles with parent figures as householders, standing in the psychological penumbra of the institution. Here the child, together with similar children, is fostered by trained parents, sees normal peers as neighbors, and learns to accept a more civilized and healthier social reality. The foster parents are paid for the work, and receive psychiatric guidance and training by the hospital or institutional staff. College credit for work in child care is given under special arrangement with nearby universities. Currently, evaluations of the effectiveness of the program are proceeding under a grant from the National Institute of Mental Health.

Summary of the Discussion by Participants

The Population: Definition and Size

The problems of the definition of deaf-blindness, and of estimates of the number of deaf-blind children in the population of the United States: Herman presented the paper (summarized in the preceding section) on the present position of the Bureau of Education for the Handicapped (BEH) and its expectations for the future. In several asides to the paper, he commented on current legislation in the area, and predicted increased support at the federal level, along with close scrutiny of present and projected programs and plans for innovations and expansion in the area of services to the multihandicapped.

The ensuing discussion was concerned principally with the actual number of deaf-blind children in the U.S., both presently and to be expected in 1980. (It should be noted that discussants seldom restricted their remarks to rubella children, but tended to include all deaf-blind children, at least by implication, in their exchanges. Smith later noted that the term "rubella-plus" might better be applied to the group, implying that it is difficult to decide precisely, in the deaf-blind population, what the etiology of the affliction may have been.) The principal point that was made was concerned with the variance of the current estimate, i,e., the range of variation around a given figure. Thus, Brewer pointed out that a figure of 5,400 children (given in his and Kakalik's paper) might be in error by 30 percent, i.e., the figure could be as small as 4,500, or as large as 7,000, for the age range 0 to 21 years. Brewer further suggested that the population of the 0 to 3 year age range is probably underestimated at present.

Spar stressed the fact that a population cannot be estimated until its defining characteristics are clearly understood. He suggested that it would be dangerous to overestimate numbers, because the less severely handicapped thus included would probably "squeeze out" the seriously afflicted. This is based on his experience that the more readily trained are always more acceptable in available programs, a point emphasized by Nash in his first paper. Several voices were raised in dissent of Spar's view, however. The major argument against narrowing and technically defining deaf-blindness was that for purposes of discussing strategies for program planning, as in the present conference, a loose and readily available definition and a correspondingly rough estimate of numbers is required. When the time comes to design the tactics of various programs, the need for stricter definitions and more exact figures will make itself felt. It was further argued that overestimation would be the less costly error, since a surplus of services could be channeled to other handicapped groups.

The Potential: Prediction and Development

The problems of predicting and developing the potential of the deaf-blind rubella population for achievement of meaningful living styles: The discussion was initiated by Smith, whose paper had outlined three nominal levels of expected performance of the handicapped population. A second, four-level classification system developed by MAC was suggested, viz.,

1. a lowest-level group requiring lifetime sheltered care,
2. a group that may be trained to achieve sheltered employment and live in sheltered environments,
3. a group that enjoys sheltered employment and semi-independent living conditions, and
4. a group achieving semi-independent employment as well as semi-independent living conditions.

This system was accepted by the group, but some cautionary remarks were made concerning the recognition that predictions of performance are never precise, and the possibility of unforeseen gains by handicapped children is always present; service personnel should, therefore, not take the predictions as final. Smith pointed out that prognosis is necessarily based on response to treatment, i.e., good achievement at elemental tasks may be the best predictor of achievement in more complex tasks. Lowell reinforced the general feeling that categorization of potential must never be allowed to "lock in" an individual to an inescapable "ultimate level" of performance.

With respect to the last point, Herman warned that predictions must not be too rigid because such categories may be written into legislation, with the result that certain benefits from which a youth may profit can be denied him. An example is that of legislation on vocational training and job qualifications, in which rigid legal classifications may eliminate handicapped persons from training or employment.

The figures provided by Smith in his paper concerning the proportions of children in various categories of expected performance, i.e., 60 to 75 percent in the lowest levels, 15 to 25 percent in the middle level, and 5 to 10 percent in the highest level, were not seriously challenged, by the Management Analysis Center may be expected to provide more exact estimates in the near future. Brewer suggested that the regional centers may have such data available. Hammer pointed out the similarity of the classification scheme, and of presently known proportions, to that of the American Association for Mental Deficiency for categorization of mentally retarded children. It may further be noted that the scheme outlines the ontogeny of the normal individual as well.

Programs: Now and Needed

The question of what programs are presently available, currently planned, or in need of planning, to deliver required services, or to provide physical facilities and human resources for delivery of services to the deaf-blind rubella children: Much of the opening discussion of this, the major conference topic, focused on the problem raised in the preceding discussion by Herman, viz., that of providing a continuum of services from childhood to adulthood, particularly of dovetailing vocational programs with academic programs in the critical period 12 to 18 years, and perhaps beyond. The insistence of several discussants on the need for such programs implied that present coordination among responsible agencies is inadequate, at least in respect to the proper blending of education and training efforts for the growing handicapped child.

As one approach to the problem of integration of efforts, Lowell proposed for consideration the idea of a central community serving the deaf-blind. This would be not a traditional, centralized institution, but rather a small community or collocation of services that would function to provide residential facilities, skilled homemakers, counselors, teachers in academic and practical arts, and medical and research facilities, providing care and services on a permanent or temporary basis depending on the individual's needs and capabilities. Response to the proposal was varied: Smith pointed to the advantages of grouping clients to reduce the current fragmentation of services and limited numbers of personnel among the regions now existing, and Lowell noted the economic advantages of communal arrangements. Herman replied that economics should not outweigh human values in program decisions. MacFarland and Hammer felt that any form of institutionalization is obsolete, if not dehumanizing.

Rieger outlined the program he is currently directing under a grant from the National Institute of Mental Health. The essence of the "satellite home" concept has been abstracted in the section on the precirculated papers (p. 7). Reception of the general method, especially the emphasis on emotional support for the maturing child as well as for his parenting figure, was enthusiastic. This led to a digression into the details of what some described as the "structure" of programs, which, as Herman insisted, should be the subject of later conferences. The present one, he felt, should give broad outline to the general types of programs required, and not be specific about details of each. Nonetheless, one aspect of Rieger's presentation was emphasized in order to provide a guideline for program planning, viz., the four elements required for adequate psychological development of the exceptional child. These are:

1. proper physical environment,
2. a proper human environment, i.e., parenting figures trained to deal with the child's needs,
3. the emotional support system in the form of expert guidance and counseling for the parenting figures and the child, and
4. appropriate education, training, and social services to normalize the child's development.

It was felt that these elements applied to handicapped as well as to disturbed children (cf. Part II of Rieger's paper, p. 97).

Lowell reminded the conference that the lowest-performing level in the deaf-blind rubella group may amount to 3,500 children, and the problem of finding surrogate parent figures with needed skills would loom very large. Taylor and Rieger agreed that the children-to-surrogate ration could be greater than one to one, but no specific ratio value was given. Laski suggested that it might be necessary to provide for each child a transcendent surrogate who would, throughout the child's life, act as both advocate and emotional resource in the interest of the child's right to normalization.

At Lowell's request, Taylor presented her paper to the group (summarized in the preceding section, p. 6) on current and projected programs for training and education of teachers of the handicapped, or of college educators in special education, as well as of para-professional personnel for special services to the handicapped, such as house parents. The programs outlined are coordinated with those in Social and Rehabilitation Services (SRS), according to Taylor. She made the additional point that consideration is currently given to retraining of teachers in certain crowded areas of special education to convert them to other areas where teacher demand is higher. With regard to funding of college training programs, Taylor indicated that so-called "block" funding was likely to eliminate training programs for problem areas in which a small number of handicapped persons are found. "Special Projects" funding procedures would solve such problems as that, if colleges will cooperate.

Lowell suggested that model or demonstration programs, based on systems like that described by Rieger, might be started forthwith, to test the validity of the concepts in the area of the deaf-blind rubella child, as compared to the emotionally disturbed children with whom Rieger deals. (At this point, a movie detailing the social interactions among disturbed children and parenting figures in Rieger's research program was shown to the conference, ending the first day's session.)

Lowell began the second day of discussion with a restatement of the intent of the conference to estimate the requirements of planning for 1980 to meet the needs of the maturing deaf-blind rubella population. Whereas the previous day's discussion centered around the largest proportion of the children, i.e., those at the lowest expected performance level, the present discussion turned to the highest-level group, that is, the 5 to 10 percent, or approximately 500 children who could be expected to lead nearly independent lives in their communities. To the question, "Would present facilities be adequate for this group?" there were mixed answers. MacFarland and Spar thought their organizations could accept many if not most of the youths in this class, but other discussants, stressing the unique problems of rubella children, were dubious. It was suggested that new, specially-trained teachers would be needed if such ongoing programs were to be modified appropriately.

Nash expressed the view that the appropriate place for education of the handicapped, at least those at the highest level, is the public school system. Smith entered the mild objection that vocational training would probably not be easily undertaken in that setting, but Laski demurred, citing the fact that the courts have never distinguished the terms "education" and "training" in this context. Furthermore, the public schools will be held accountable for at least overseeing the education of such children, if not for providing teachers and facilities from local funds. Laski further stated that neither the degree of the handicap nor the cost of education had ever been accepted by the courts as valid reasons for not educating a child. Other participants cited specific cases in law that appeared to validate Laski's claims.

The question of the present availability of teachers in special education, and of projected expansions of human resources in this area, was raised by Lowell. When Hammer cited the role of the case manager (see his paper, p. 84) in guiding the training of service personnel, Brewer was asked to compare the case manager function with the "direction center" program advocated by Rand.

The Direction Center, as Brewer was careful to note, is an agency that contacts the family of the handicapped child as early in the service process as possible, in order to sort out the varieties of cases according to apparent needs, and send them to the appropriate treatment or training agencies. Other than this service, and that of maintaining records of individuals served, the Direction Center would do nothing more. Brewer declared that saddling such centers with other service functions would lead to the kind of fragmentation of services from which present agencies are suffering. Moreover, when the service is restricted to information-giving and record-keeping, the technical level of the staff need not be high. Costs of such a center should be about $100.00 per child per year, Brewer estimated. Rieger noted that he had included in his treatment programs a similar service, with some success, and would aid in further consideration of such an agency.

Returning to the question of numbers of teachers presently available or now in training for the deaf-blind rubella group, Taylor reported that the current program started slowly but would provide, as it has this year, as many as 85 teachers per year. The question of numbers, as Brewer pointed out, may not be so important as the distribution of teachers among primary, secondary, or vocational training specialties. Other sources, such as the conversion of regular trained teachers to special education, were discussed. The provision of greater emotional support, e.g., in the form of administrative counseling for such teachers, was suggested to reduce the high attrition rate that resulted from the emotional stress of working with severely handicapped children.

One of the major problem areas considered by the participants, for which no present program seems to provide a satisfactory solution, is that of providing care for the approximately 3,500 children in the lower levels of performance. It was not possible to draw up specifications for the type of person required for the job, but the task requirements appeared to be those of special child care, ability to communicate with the deaf-blind, homemaking, and ability to teach the fundamentals of personal care.

Coupled with these would be some ability to observe and report progress in learning to supervisory personnel and great warmth and compassion for the child, however afflicted. In short, a kind of ideal parent surrogate would be desirable to care for three or more of the handicapped children who are currently, as several participants put it, "on the back wards of institutions across the country." Such persons would not necessarily be licensed teachers or para-medical specialists, but they should certainly have some training in both specialties beyond the high school level. In this area, Rieger's program has made significant contributions.

Lowell offered the suggestion that the total number of individuals required to work with the 3,500 lowest-level children should be 700 to 800. Smith responded with an amendment, to the effect that three or four types of trained individuals would be needed, e.g., group home managers, foster parents, or parental counselors. The question of the source of such personnel, and the degree of training they might require (i.e., whether B.A. level, M.A. level, or A.A. level) was not answered.

A final point of discussion of the session was made by Laski at Lowell's request. Concerning the very severely handicapped person who may not show educability of an elementary sort, Laski declared that, whereas current practices rely on educational rights, not medical entitlements, federal legislation appeared to be tending toward partial or full support of such persons in educational, medical, and welfare (income) benefits through childhood and adulthood. In other words, society would be asked to provide whatever support the handicapped person or his family could not assume, in order that he live as normal a life as possible.

Reply by the Regional Coordinators and Other Expert Observers

Lowell invited the nine Regional Coordinators, along with three other experts attending the conference as observers, to respond to the papers and discussion with criticisms, questions, or suggestions. In the ensuing period, a number of important points were raised, some commonly voiced among the observers, others made individually.

Of the commonly repeated points, the following appeared to be salient:

1. The need for better evaluative studies of the deaf-blind rubella populations in the regions remains, and grows more urgent.
2. The probability is that the figure of 5,000 children given presently is too low, perhaps half as large as may eventually appear.
3. Teacher training programs are strongly supported by the coordinators; however, placement of teachers in certain of the regions is difficult. Some areas cannot attract current graduates, whereas others may be embarrassed with them.
4. Of constant concern is the question of the source of funds and their probability of continuing, given that program expansions are begun. The likelihood of attracting and retaining good candidates for service positions is powerfully controlled by the stability of programs from year to year.

Several experts raised important points not covered by others. Among these were the following:

1. It is well to speak of interaction among the various governmental agencies at federal, state and local levels, but a specific set of guidelines for such activities needs to be drawn. Currently there are flagrant cases of non-cooperation on record.
2. Parental advocacy of cases of deaf-blind or other multihandicapped children is an ongoing and growing phenomenon in the midwestern region. The pressure for affirmative action programs is mounting.
3. The deaf-blind rubella children should probably not be consolidated with the other multihandicapped children. The distinctive problems of the former should be handled separately by service and teaching agencies.
4. A carefully-wrought public relations campaign for local public schools should be mounted to persuade them to upgrade their present treatment and future commitment to the handicapped children.
5. Responsibility for the design of programs discussed in the conference should be divided among committees of experts, e.g., to set up plans for teacher training, describe models of service delivery, and propose modifications of curriculum development to accommodate the maturing handicapped population.
6. The present conference should devote the remainder of its time to outlining estimates of the needs of the rubella group in various categories of life activities. Until the needed services are stated along with quantitative estimates of the time required for them, recommendations on the numbers and types of service personnel would be idle.
7. Closer ties between childhood and adult programs are needed to promote smoother transitions of service as the individual matures.

The Construction of a Table of the Distribution of Time for Various Services and Programs for the Deaf-Blind Rubella Children

The general and specific points raised by the Regional Coordinators and others were accepted by the conference participants as generally valid. Lowell felt that one suggestion deserved immediate action, viz., that of estimating the needs of the rubella group for specific programs and services. Accordingly, the remainder of the day was devoted to the construction of a time distribution chart to show the number of hours per week per child that would be needed for the delivery of various kinds of education, service, or training. The rubella group was broken down by age and expected performance level to improve precision of the estimates.

The Regional Coordinators were asked to take the table thus constructed and enter in each cell the number of hours per week per child that they judged would be needed for effective program delivery in 1980. Preliminary estimates on this basis were handed to Dr. Lowell on the following morning of the conference, but some experts expressed dissatisfaction with the definitions of the programs, and with their competence to make estimates. Accordingly, Lowell suggested that new tables and accompanying definitions could be sent to each administrator, with the expectation that satisfactory estimates would be returned to him with all speed, for inclusion in the present report.

Table I shows the results of the second set of estimates. The Management Analysis Center categories of expected performance level are those described in Section III (p. 9) of the present summary. The services of programs shown are described as follows:

Communication
A structured service program which is designed to create or improve the capacity of a child to receive information in some form of symbolic structure (such as gesture or oral expressive communication) and/or to create or improve the capacity of a child to respond to such stimuli in a manner understood by others.

Social/Economic
A structured service program designed to provide a child with the basic skills required to meet all activities involved in daily living at the identified level of potential (such as toileting or counting money).

Psychological/Social
A structured service program whose objective is to enable a child to live both affectively and effectively in his (her) community and/or environment, and to develop the capacity of a child to shape the degree of participation in his (her) environment (such as peer group intervention sessions, deaf-blind/normal children group dynamics or community resident counseling/intervention).

Psychological/Sexual
A structured service program designed to develop the body image and awareness of a child and his (her) physical adequacies and inadequacies in relation to peers, to members of the opposite sex and to both adult and child members of the general population (such as basic hygiene instruction or pre-marital genetic counseling).

Pre-Vocational/Vocational
A structured service program which is designed to develop specific identified skills of a child in such a manner that they can be matched to some specific form of employment which is both satisfying to the child and productive in a work environment.

Other
Programs suggested by respondents were: Recreation, Physical Therapy, Occupational Therapy, Experiential Play, Cognitive Skills, Sensory-Motor Integration and Development, Adaptive Physical Education, Gross and Fine Motor Skills, and Structured Stimulation.

The entries in the table (see Table I, p. 17) are median values for eight respondents, of whom seven were administrators and one was a teacher of the deaf-blind. The median is the value above and below which 50 percent of the values lie, and represents a good measure of the expected or most probable value for a small sample. The values below each median, in parentheses, are the semi-interquartile ranges for each median. This measure of dispersion serves to gauge how well the judges agree in their estimates of times for the entries. If the range is small, agreement is good; if large, agreement is poor.

Respondents were asked to make their estimates on the basis of a 40-hour week, and their individual totals were indeed 40 hours for each category and age group. In taking medians, however, deviations from 40 hours were produced, but no very significant differences resulted, except in Group A of the third category.

The table tells us that the judges expect that one-third of the time (12 hours) of the youngest children (Group A) in the lowest-level category will be devoted to communication skills, whereas only about three percent of their time (1 hour) will be consumed by pre-vocational or vocational training. Depending on the number of children in this group, one may then estimate the number of teachers or training specialists to be recruited for these services. If one takes Brewer and Kakalik's figures for all deaf-blind children from 0 to 11 years (see their paper, Table 2), a figure of 1,300 children results. Taking Smith's estimate of proportion of children in various levels of performance, and assuming that 50 percent of the age group will be found at the lowest level, the number of children to be serviced in the foregoing example will be 650. Given that one specialist can treat five such children, the number of specialists required would be 130, if each specialist spent 40 hours per week with them. Because the communication skills specialist must spend one-third of her time with the lowest-level youngest group, whereas the vocational specialist spends only three percent of her time with the same group, the number of specialists required in any service or category will obviously vary according to the needs as predicted by the table entries.

The foregoing is, of course, a speculative exercise so far as the figures are concerned. Brewer and Kakalik's estimate is almost three times that of Dantona's (see Hammer's paper, Table 2), and Smith's figures may soon be revised in a forthcoming report from the Management Analysis Center.

It has already been noted that the entries of Table I are estimates by experts in the field, but the opinions of more experts would improve the reliability of such estimates greatly. The form of the exercise is, nonetheless, reasonable. Given more reliable data, useful estimates of the necessary human resources for the services and programs outlined can be made. Again, the reader must be warned that assumptions are made that agreement can be reached on which programs and services are appropriate, on what level of skill the personnel in those services should have, on the physical facilities required, and on the optimal distribution of such facilities and personnel throughout the country. Supportive or adjunctive services and programs are required as well, of course, and must ultimately be added to the large picture.

TABLE 1

ESTIMATES (FOR 1980) OF THE DISTRIBUTION OF TIME SPENT PER WEEK ON A GIVEN PROGRAM OR SERVICE FOR THE DEAF BLIND RUBELLA CHILDREN

SERVICES/PROGRAMS	MAC CATEGORIES OF EXPECTED PERFORMANCE LEVEL											
	CUSTODIAL/ SHELTERED LIVING			SHELTERED EMPLOYMENT/ SHELTERED LIVING			SHELTERED EMPLOYMENT/ SEMI-SUPERVISED LIVING			SEMI-INDEPENDENT TO INDEPENDENT EMPLOYMENT AND LIVING		
	GROUP A HOURS	GROUP B HOURS	GROUP C HOURS	GROUP A HOURS	GROUP B HOURS	GROUP C HOURS	GROUP A HOURS	GROUP B HOURS	GROUP C HOURS	GROUP A HOURS	GROUP B HOURS	GROUP C HOURS
COMMUNICATION	12 (4.5)	10 (2)	6 (2.5)	11 (3)	10 (1.5)	5 (2)	6 (5)	7 (2.5)	4 (1)	10 (5)	7 (3)	3 (3)
SOCIAL/ECONOMIC	5 (3.5)	8 (3)	7 (4)	9 (4)	6 (2)	4 (1)	5 (3.5)	5 (1)	4 (1)	6 (3)	5 (1)	4 (1)
PSYCHOLOGICAL/SOCIAL	6 (2.0)	9 (2.5)	10 (3)	6 (1)	6 (2)	6 (1.5)	6 (1)	6 (1.5)	5 (1.5)	7 (2)	5 (2)	6 (2)
PSYCHOLOGICAL/SEXUAL	5 (2.5)	4 (2.5)	5 (2)	5 (1.5)	6 (1.5)	5 (1.5)	5 (1)	5 (2)	5 (1)	5 (1)	6 (1)	5 (1)
PRE-VOCATIONAL/ VOCATIONAL	1 (1.5)	4 (2.5)	3 (3)	1 (1)	9 (2.5)	14 (4)	2 (1.5)	10 (2.5)	19 (2)	2 (1)	12 (4)	17 (6)
OTHER (e.g., Recreation, Physical Therapy, Cognitive Skills)	7 (5.5)	7 (5.0)	4 (3.5)	4 (6)	5 (3)	4 (3)	4 (6)	4 (3)	1 (2.5)	4 (5)	3 (4)	1 (2)
TOTAL HOURS: (40)	36	42	35	36	42	38	28	37	38	34	38	36

NOTES:
1. Age groups within categories: A–0 to 10 yrs: B–11 to 17 yrs: C–18+ yrs.
2. Entries are median values for 8 judges, including 7 administrators of programs for the deaf-blind, and one teacher of the deaf-blind.
3. Values in parentheses are semi-interquartile ranges, a measure of dispersion of the estimates about the central value.
4. Median values were rounded to whole numbers, ranges to half-hours.
5. Whereas the totals added up to 40 hours for each judge, averaging of values produced some deviation from 40, not significant in most cases.

Identifying and Servicing the Deaf-Blind

Serving the Deaf-Blind Population: Planning for 1980

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Introduction

While rubella is only one of the many causes of deaf-blindness, the rubella epidemic of the mid-1960's has contributed untold pain, sorrow, and expense for this society, including more than a quarter of the approximately 4,400 young deaf-blind persons who have been identified, and tens of thousands of children with less severe but very major handicaps. This much larger than average cohort of handicapped contains children who are all approximately the same age, and this fact has created major problems for the service system in responding to their needs as the children progress from needing medical and preschool services to needing very special types of education, to perhaps needing vocational, residential or other services, when they become older teens in 1980. The results of that epidemic were not all tragic, however. It did have the positive effects of galvanizing government officials into action to create a rubella vaccination program, the Regional Centers for Deaf-Blind Children and the National Center for Deaf-Blind Youths and Adults; those three programs should result in better services for future children and for deaf-blind children and adults, including those whose handicaps were not caused by the rubella epidemic.

The much larger than average cohort of deaf-blind children, as it progresses upward in age, punctuates some very major problems of the fragmented system serving handicapped children and youth, i.e., underdeveloped prevention services, lack of information needed for effective planning, and failure to mobilize far enough in advance to meet known future needs of the deaf-blind handicapped population.

In this paper, we briefly consider the planning required to meet the needs of young deaf-blind persons in persons; illustrate the humanitarian and economic desirability of prevention; and we make projections of the 1980; we discuss the need for information about and control of the service system; note the need to improve identification programs, especially for older deaf-blind number of young deaf-blind persons and the cost of serving them in 1980.

For a more detailed description of the system serving handicapped persons, documentation of its problems and numerous recommendations for improvement, refer to our Rand Corporation reports, *Services for Handicapped Children: A Program Overview*, R-1220-HEW (May 1973); and *Improving Services to Handicapped Children*, R-1420-HEW (May 1974).

Service System Information and Control

Planning for services to deaf-blind persons is severely hampered by a lack of relevant information and a lack of coordination and control of the service system due to its fragmented nature. Information on the prevalence and needs of deaf-blind persons over the age of twenty-one years is practically nonexistent; nationally available data on younger deaf-blind persons is much better but still deficient. For example, data on the nature of the "deaf-blind" person's degree of hearing and vision impairment, degree of functional sensory ability, degrees of other types of functional ability, and presence and degree of additional handicaps—such as mental retardation— may be known to professionals serving the individual, but have not been fully aggregated nationally for planning purposes. Work on the costs of alternative service mechanisms is lacking, and information on the effectiveness of services is severely deficient. Without well developed planning information linking the deaf-blind people in need of services with the many different groups of officials responsible for making policies, the appropriate services cannot be adequately planned for and made available. Deaf-blind children, perhaps more than other handicapped children, require more, more specialized, and usually more expensive services. The

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nature of these services is such that better planning is required since these services are not normally in high demand and hence are scarce. Due to recent federally sponsored efforts, information has improved markedly, and will soon improve more, but there is still a long way to go.

The young deaf-blind population has been relatively more fortunate than the handicapped population in general with respect to the institutionalization and federal funding of Regional Centers for Deaf-Blind Children throughout the nation. The Regional Centers are intended to identify deaf-blind children and offer comprehensive diagnostic and evaluative services, maintain a registry, develop consultative and training programs for both parents and service personnel, develop new programs and services where they are needed, and coordinate services offered by other existing agencies. The federal government also funds a National Center for Deaf-Blind Youths and Adults. The National Center is intended to provide comprehensive services through residential facilities, provide consultative aid to other organizations serving deaf-blind persons, demonstrate methods of service, train personnel, and conduct research on services to the deaf-blind. Federal creation and support of these centers is justified due to the very low incidence and special needs of the deaf-blind population, which means that individual states generally have too few of them to mount an effective program providing the specialized intensive and comprehensive services they need. Even with interstate regional centers, however, we understand it has sometimes been difficult to obtain highly qualified staff for the service programs because the programs are expanding faster than new professionals are being trained.

In their study of information system requirements for the Regional Deaf-Blind Centers, Exotech Systems, in June, 1971(3), provided some valuable insights into the information requirements and problems of the deaf-blind population. According to Exotech, information about this most severely handicapped subset of the population in 1971 was "by any standard poor in quantity and low in quality." The study made positive recommendations about what might be done to improve matters. A Deaf-Blind Center Information System was advanced as a prototypical design for not only the deaf-blind, but for all handicapped persons at some future point in time.

With respect to the system serving deaf-blind children, certain qualitative observations are possible from the information, coordination, and control points of view. The extra service burden represented by the unexpected addition of the 1963-1965 rubella cohort is easily seen as a much heavier than normal load or disequilibrating force. There is not one integrated service system, but rather a number of system fragments. Because of this structural fragmentation—and inadequate information, coordination, and control—the system is moved to respond in piecemeal fashion with the result that the added service load is actually sensed by first one fragment and then another in the overall system. And segments of the service system sometimes do not sense the heavier load sufficiently in advance to allow the development of added service capacity and trained personnel.

For vocational and other services required by teenagers and young adults, there is still time to prepare for the added load, but the education system has already been seriously impacted by these children. Doctor and Davis make several pertinent observations about the impact of the rubella cohort when it came into contact with the educational system.(2) Among other points, the generally different character of the population, having as it did a high proportion of multihandicapped and sensory impaired children, was not appreciated. The learning problems demonstrated by this population were far different than those the system had learned to cope with in terms of the polio afflicted cohort of some ten to fifteen years earlier. The polio cohort was more like a "normal", i.e., nonhandicapped, cohort in terms of its educational needs than was the rubella cohort.

The question, with respect to all the fragments of the system not yet seriously affected, is what is being done now in anticipation of the known but unrealized need for service? The question, with respect to those fragments of the system most heavily loaded by the cohort or where the cohort has already passed on through, is what adjustments are being planned to change the level of services currently being delivered to find and serve those coming along who in the past would not have received services, e.g., increasing attention to finding more children and serving those who are less severely handicapped, or decreasing the level of services back to a steady state reflecting the expected number of seriously impaired children who will in the future require services? For instance, some component of service demand will doubtless be chronic, and for children in that component one might work to provide full coverage to all who can be found. Another component of service demand will probably be recurring, as in the case of another epidemic (a decided possibility given the dearth of sustaining rubella prevention services currently being delivered) or some unknown horror that might render a portion of an unborn cohort deaf and blind. Finally, some component of today's demand, a demand generated by the extraordinary load of the 1963-1965 rubella cohort, is genuinely regarded as "nonrecurring", and once that proportion has been served, service resources no longer needed can be reallocated (much as was the case with polio research resources in the post-Salk era).

Unfortunately, these rather obvious adjustments may not take place given the poor control evident in the present system. The Regional Centers are a step in the right direction, but they do not control the majority of the service system. The nation may continue training elementary-level special education personnel for the deaf-blind when actually more personnel to help with teenaged and adult services are needed in the future. And most painful of all, the system may not have "learned" very much from the experiences generated by the present rubella cohort, for use in some subsequent disaster; and the proverbial wheel will once again come rolling off the drawing boards at some time in the future.

We need to concentrate especially on means to increase lead time or advanced planning and preparation for future service needs. Short or no lead time situations are undesirable for several reasons. Unanticipated problems tend to produce solutions outdated before they are implemented, e.g., solving yesterday's problems, or solutions that require far more resources than would have been necessary had there been adequate preparation. With increased lead time, those responsible for a system may work out better, more appropriate, or less costly solutions in advance. Resource allocation decisions take time; with insufficient lead time, resources are more likely than not to be inefficiently and ineffectively allocated—poor allocations based on poor or nonexistent feedback of information about the actual situation.

An Alternative to Aftercare

Since the topic of this paper is planning for service to deaf-blind persons in 1980, it is appropriate to consider prevention as an extremely desirable alternative to serving persons after they become deaf-blind. Not all cases of deaf-blindness can be prevented, but rubella is an excellent example of a major cause that can be prevented, and prevented very economically in relation to the high costs of aftercare. Yet current prevention programs are insufficient and flagging.*

It took a major epidemic in the mid-1960's to force official attention to focus on the case of rubella, but in the absence of subsequent catastrophes, maintenance of this attention and related activity has waned. Not only does it appear to take a human crisis to galvanize system-level attention to a specific problem, but the maintenance of attention is not assured in the absence of other crises.

The importance of long-term maintenance of preventive activities is easily stressed in a simple cost exercise designed to relate prevention costs to service costs for handicaps resulting from inadequate prevention. The rubella epidemic of 1963-1965 left an estimated 20,000 to 30,000 handicapped children in its wake, a tragedy that society will be paying for in many significant ways for years to come.(4) In his analysis, Donald Calvert estimated the special educational costs alone associated with the impaired subset of the epidemic population.(1) We have made our own more conservative estimates based on special education expenditure data accounting for the discounted incremental costs about the cost of regular education. As can be seen from Table 1, Calvert's and our estimated special educational costs differ significantly; however, even taking our intentionally conservative estimate as a basis of comparison, there is a striking difference between the $202,000,000 in increased special education costs due to that one rubella epidemic and the $41,600,000 total authorized under the Rubella Immunization Program.** And we have not even considered increased costs of services other than special education in the calculation, not to mention the degradation of quality of life inflicted by the handicap.

The urgency of such preventive programs is manifest if we look only at the high annual cost associated with the special education for deaf-blind children: from $12,000 to $14,000 per child.*** For the estimated 1,250 deaf-blind children resulting from the 1963-1965 rubella epidemic alone, this represents an annual outlay of about $15,000,000 (using the low estimate).

The messages from this example and discussion are clear: rubella can be prevented; rubella-caused handicaps are expensive; prevention is decidedly cost-effective; and attention to the rubella immunization program is flagging, with potentially tragic and costly results. The main point of this illustration is that in planning for services for deaf-blind persons in 1980, attention should be paid both to serving those already handicapped and to those who might in the future become so if appropriate measures are not taken.

Young Deaf-Blind Population Projections – 1980

The population of identified young deaf-blind persons is projected to grow from a total of 4,414 in the year 1973 to perhaps 5,400 in the year 1980. Table 2 gives a breakdown by age. The 1973 data for the cohort aged three through eighteen are thought to be of relatively high quality due to efforts of personnel throughout the country in the Regional Centers for Deaf-Blind Children. However, we suspect that the number of known deaf-blind children less than age three and adults over age eighteen is relatively low due to the lack of identification of persons in those age groups.

In looking at the 1973 data for the relatively well-identified cohort aged three to seventeen, note the peak in the population in the upper-elementary school ages due to the rubella epidemic in the mid-1960's; and also note that the number of identified young deaf-blind persons not born in rubella epidemic years is relatively constant at about 140 per year (an average of 138 per year for children now aged three to five, and an average of 142 per year for children now aged twelve to seventeen years). In making our projections to the year 1980, we assumed the following: the quality of infant and adult identification programs would not improve markedly; the 1973 identified population aged three or above would age the seven years to 1980 with almost no deaths (note that only 123 of the identified young deaf-blind persons are over age twenty-one; the number of identified deaf-blind children aged zero to two in 1980 will be approximately the same as it is in 1973; and the number aged three to nine in 1980 will be the approximately 140 per year that now prevails for young persons not born in rubella epidemic years. These projections to 1980 thus assume no major new rubella epidemics or other disastrous events that will cause an abnormally high number of persons to be deaf-blind, and they also assume no major progress in the prevention of deaf-blindness. Given the current rubella vaccination program that has protected many but left many others unprotected, it seems most likely that this major cause of deaf-blindness will be partially controlled but still a menace in 1980. Of course, all projections into the future are exercises in predicting the unknown and are subject to uncertainty. In this case, we feel that the 5,400 estimate for young persons is the most likely number, but a lower bound would be the currently identified 4,400, and 7,000 would be an upper bound unlikely to be exceeded without the creation of a comprehensive identification program for adults. That upper bound of 7,000 might be reached if, for example, we have another major rubella epidemic between now and 1980.

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* See Chapter 6 of Rand Report R-1420-HEW (May 1974), for several recommendations for improvement.

** Section 314(e) of P.L. 89-749.

*** The low estimate is that used by California's School for the Blind in their deaf-blind program, the high figure is that reported by Calvert for Massachusetts' Perkins School for the Blind's Program in 1969. (No allowance for inflation is made.)

TABLE I

ESTIMATED COSTS FOR 13 YEARS OF SPECIAL EDUCATION OF HANDICAPPED CHILDREN FROM THE RUBELLA EPIDEMIC OF 1963-1965[1]

HANDICAP	NUMBER	UNDISCOUNTED TOTAL COST: CALVERT ESTIMATE	DISCOUNTED TOTAL INCREMENTAL COST: RAND ESTIMATE [2]
Visually impaired	5,500	$250,250,000	$35,500,000
Hearing impaired	12,000	468,000,000	77,400,000
Deaf-blind	1,250	227,500,000	81,000,000
Retarded/crippled	1,250	48,750,000	8,100,000
TOTAL	20,000	$994,500,000	$202,000,000

TABLE 2

THE 1973 AND 1980 YOUNG DEAF-BLIND POPULATION BY AGE

AGE RANGE (YEARS)	NUMBER IDENTIFIED 1973[3]	PROJECTION OF NUMBER, 1980[4] (TO NEAREST 100)
0-2	60	100
3-5	415	400
6-8	803	400
9-11	1438	400
12-14	413	700
15-17	439	1200
18-21	315	900
21+	123	900
Unknown or unreported age	408	400
TOTAL	4414	5400

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[1] Source: Donald R. Calvert, Report on Rubella and Handicapped Children, Department of Health, Education, and Welfare, Bureau of Education for the Handicapped, Washington, D.C., May 1969.

[2] Note: Rand estimates are based on expenditure data contained in Chapter 6 of Rand Report, R-1420-HEW, May 1974. Thirteen-year costs are discounted at eight percent to time of birth.

(3) Dantona, Robert. Demographic Data and Status of Services for Deaf-Blind Children in the United States. In C. E. Sherrick (ed.), 1980 IS NOW: A Conference on the Future of Deaf-Blind Children. Los Angeles: John Tracy Clinic, 1974.

[4] See text for our method of projection.

The change in the age distribution between 1973 and 1980 is marked. As can be seen in Table 2, the number of children of elementary school age declines sharply while the number aged fifteen to twenty-one nearly triples and the number of young deaf-blind persons identified over age twenty-one goes up seven-fold. The clear implication is that adult residential care and other service programs for teens and young adults, such as those concerned with vocations, must begin to act now to be ready to serve the rapidly growing known teen and young adult deaf-blind population in 1980.

In planning for services in 1980, it is also necessary to consider the various degrees of handicap within the overall young deaf-blind population. Some are both totally blind and profoundly deaf, but many have at least some degree of hearing or vision. Some have only sensory impairments, but many have other handicaps such as mental retardation. Given the poor quality of available data on the degree of deafness and blindness and the presence of other handicaps, estimates of the fractions of the 4,414 young deaf-blind persons possessing varying degrees of handicap must be based on subjective expert opinion rather than on hard data. Benjamin F. Smith, the Director of the Perkins School, has ventured that approximately sixty percent to seventy-five percent are "middle trainable and below" in terms of what he calls "practical functioning levels," approximately fifteen percent to twenty-five percent are "upper trainable though lower educable", and approximately five percent to ten percent are "middle educable and above". (5)

Using the optimistic end of Smith's percentage ranges, of the projected 5,400 identified young deaf-blind persons that may be identified in 1980, only 500 would be middle educable or above, while 1,400 would be upper trainable though lower educable, and 3,500 would be middle trainable or below in practical functioning levels. Of course, for an individual handicapped person, "practical functioning" is a complex scale having many different dimensions. The three crude categories of practical functioning used above serve only to give necessary overview information about the young population. For planning to meet the service needs of an individual, in-depth personal evaluation of the many different components of "practical functioning" must be made.

We have not ventured any estimate of the size of the older adult and geriatric deaf-blind population due to the dearth of data on the subject. While the majority of young deaf-blind persons have probably been identified by the ten Regional Centers for Deaf-Blind Children, the majority of older deaf-blind persons are not identified. Two counteracting forces make it difficult to make estimates of the size of the older deaf-blind population. Simply applying the prevalence rate for the young to make estimates for the older population would mean the total deaf-blind population was two and a half times as large as the young deaf-blind population (since the total U.S. population is about two and a half times as large as the population aged zero to twenty-one). However, that simplistic approach is likely to be highly inaccurate since the death rate for multihandicapped persons is probably higher than that for normal persons, and since it is well known that the prevalence of hearing problems in the population increases with age, as does the prevalence of vision problems. Without better data, we cannot say with any reasonable accuracy how many older deaf-blind persons exist, and what it would cost to serve them.

Cost of Serving Young Deaf-Blind Persons in 1980

Estimates of the size of the 1980 young deaf-blind population are one of the more accurately predictable factors affecting the overall cost of service. Perhaps the most important unpredictable factor is the level of effort government will choose to make in providing service to deaf-blind persons. Will government elect to spend, say, $5,000 per person, per year on the average and thus be able to provide only residential care for those in institutions and minimal services to those whose daily living expenses are privately financed? Will government elect to spend, say, $10,000 per person, per year and thus provide services of modest quality? Or will government elect to spend the perhaps $15,000 per year, per person on deaf-blind children and youth needed so they can approach the maximum of their potential ability? Note that if the inflation rate averages five percent for the next seven years, agencies that today are spending $12,000 to $14,000 per year, per child for the higher quality services must spend approximately $16,000 to $19,000 in 1980 to buy the same services.

In aggregate terms, if the projected number of 5,400 young deaf-blind persons were identified and served in 1980 at an average cost per year of $5,000, then the annual expenditure rate would be approximately $27,000,000. If an average of $10,000 were to be expended per person, then the annual expenditure rate would be $54,000,000. If an average of $15,000 were expended per person, then approximately $81,000,000 per year would be required in 1980 for services to young deaf-blind persons. Yet, that much is probably required per year, at least during the years when children and youth need to be educated, if this segment of our population is to approach its maximum potential level of ability. And nearly all of those who have been identified are less than twenty-one years old. The needed expenditures would be still higher if society elected to identify and provide special services to deaf-blind persons in the older adult and geriatric population.

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1. Calvert, D.R. Report on Rubella and Handicapped Children. Department of Health, Education and Welfare, Washington, D.C., May, 1969.
2. Doctor, P.V. & Davis, F.E. Educational Impact – The 1964-65 Rubella Epidemic in the United States. American Annals for the Deaf, 1972, 117, 11-13.
3. Exotech Systems, Inc. An Information System for Regional Centers for Services to Deaf-Blind Children. BEH/OE/HEW Contract No. OEC-0-70-4923, Washington, D.C., June 30, 1971.
4. Sever, J.L., et al. Epidemiological Observations of Rubella in the Collaborative Perinatal Research Study. Proceedings of the International Conference on Rubella Immunization, Stockholm, Sweden, February 18-20, 1969.
5. Smith, B.F. Potentials of Rubella Deaf-Blind Children. In C.E. Sherrick (ed.) 1980 IS NOW: A Conference on the Future of Deaf-Blind Children. Los Angeles: John Tracy Clinic, 1974.

Demographic Data and Status of Services for Deaf-Blind Children in the United States

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Geographical Distribution of Deaf-Blind Children

The Regional Centers for Deaf-Blind Children, since their inception in June of 1969, have located 4,414 deaf-blind children. Deaf-blind children are defined as:

> *. . . children who have auditory and visual handicaps, the combination of which causes such severe communication and other developmental and educational problems that they cannot properly be accommodated in special education programs solely for the hearing handicapped child or for the visually handicapped child.* (1)

Deaf-blind children have been located in all fifty states including Guam, the Trust Territories, Puerto Rico, and the Virgin Islands. (See Table I)

Program Enrollment

Of the 4,414 children located, 3,461 are receiving services through the more than two hundred programs or projects funded under the Regional Centers. (See Table II). These services include the following:

1. full-time educational programs (residential or day)
2. part-time educational programs (residential or day) including:
    - intensive respite care
    - educational assessment
    - summer camp
    - diagnosis and evaluation

There are 947 deaf-blind children not enrolled in any program at this time. This includes the 318 deaf-blind children in the California State Hospitals.

Age Distribution

The age distribution of 4,096 deaf-blind children is as follows:

CHILDREN

AGES	NUMBERS
0 - 2	60
3 - 5	415
6 - 8	803
9 - 11	1,438
12 - 14	413
15 - 17	439
18 - 21	315
21+	123
Unknown Birth Date	90
Sub-Total	4,096
In California State Hospitals (At this time ages unreported)	318
TOTAL	4,414

See Table III for age distribution and numbers of children served by regions. Table IV shows the current service pattern on a regional basis and the estimated number of deaf-blind children served during program year 1973-74.

Table V is a supplementary fact sheet which projects the estimated number of deaf-blind children to be served through fiscal year 1975 including appropriated budgets. Table VI shows the approved funding by Regional Centers from fiscal year 1969 through fiscal year 1974.

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1. Centers and Services for Deaf-Blind Children. Proposed Rules, Part 121c.37. Federal Register, Volume 38, Number 196. October 11, 1973.

Accomplishments for Fiscal Year 1973

In school year 1973-74, the Deaf-Blind Program directed its efforts toward expanding its services through eleven Regional Centers by providing:

1. Full-time educational services to 1,903 deaf-blind children enrolled in school year programs.
2. Diagnostic and educational assessment services to 1,145 deaf-blind children and their families. This includes an estimated 500 children in the Home Correspondence Course.
3. Short-term and part-time educational services to 784 deaf-blind children. These are programs providing more than thirty hours/year service but not more than three days per week/year such as summer school and intensive interim care.
4. Counseling services for 3,000 parents were provided and a parent Home Correspondence Course was field tested.
5. In-service training for approximately 1,200 teachers, aides, and parents.

Expected Accomplishments for Fiscal Year 1974

Utilizing fiscal year 1974 funds ($14,055,000), during the school year 1974-75, the Deaf-Blind Centers Program is expanding its services to provide:

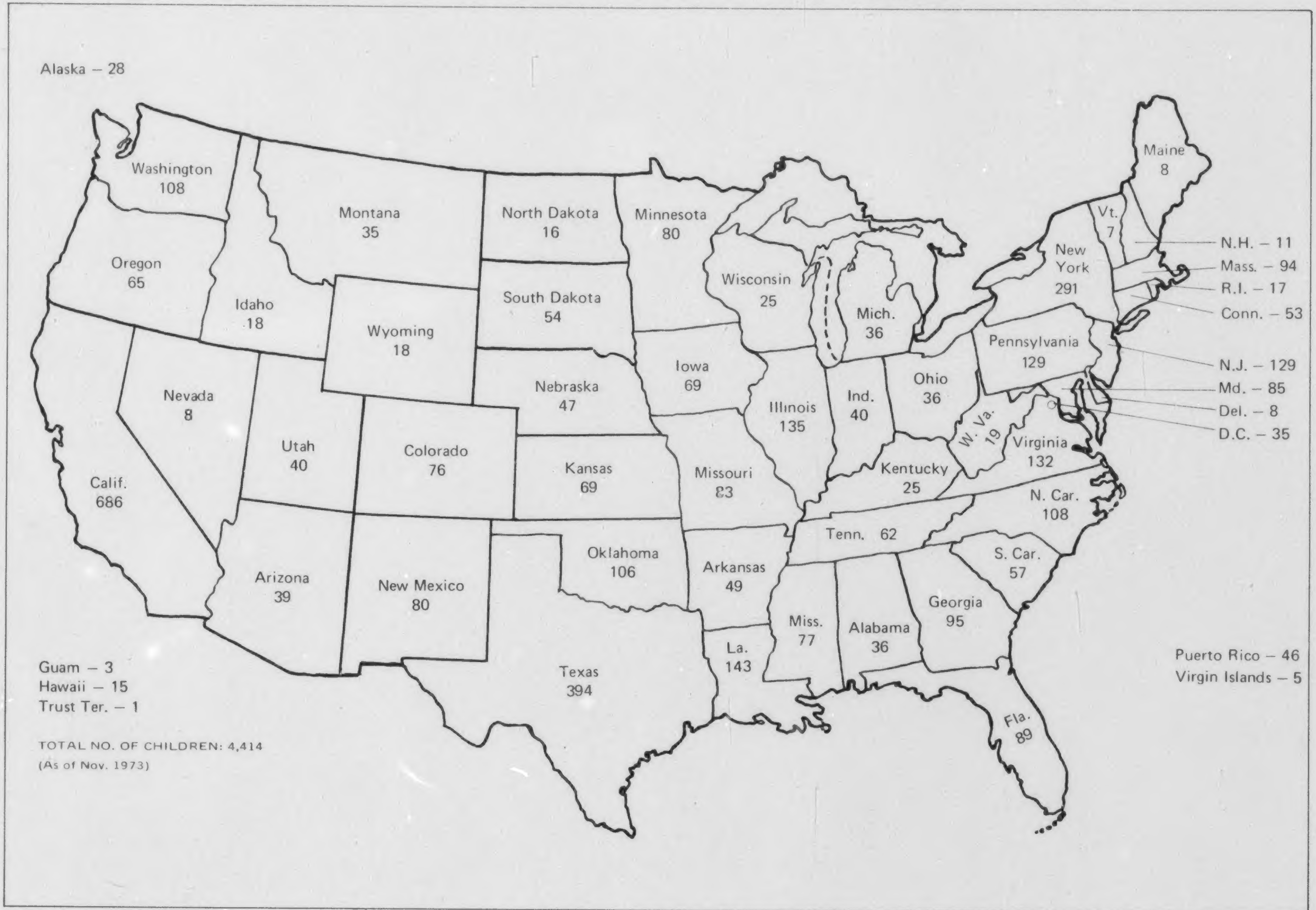
1. Full-time educational services for an additional 700 deaf-blind children increasing the total from 1,900 to 2,600 children enrolled in school year programs. The approximate cost is $4,600 per child.
2. Diagnostic and educational assessment services for 700 additional (new) children.
3. Short-term and part-time educational services for an additional 200 deaf-blind children making the total 700 children enrolled in part-time school year programs. Children are phased out of this category into full-time programs.
4. Counseling services for 3,000 parents will be provided and a Home Correspondence Course for parents of preschool and elementary school age deaf-blind children will be made available to 2,000 families.
5. In-service training for 3,000 teachers, aides, and parents.
6. A joint National Registry of Deaf-Blind Children developed in cooperation with the National Center for Deaf-Blind Youths and Adults.
7. Technical assistance program efforts geared to development of state by state plans for individual child services support. Activity will concentrate on twenty-five states having over ninety percent of the deaf-blind population.
8. Deinstitutionalization: A demonstration model for selected regional centers (2) will be developed for removing deaf-blind children ages 0-21 from state hospitals for the retarded by identifying and providing appropriate alternative placements for them.
9. Vocational education including identification, planning and implementation of pilot projects in selected regions for multihandicapped children, children in residential institutions, and those being deinstitutionalized.
10. A series of workshops for medical and clinical personnel such as pediatricians, ophthalmologists, optometrists, otolaryngologists, audiologists, psychologists, speech therapists, etc.
11. A national program of temporary assistance for parents of unserved children through a home correspondence information and assistance program. Home correspondence will be followed by visits from the staff of the appropriate regional center.

Plans for Fiscal Year 1975:
Budget Appropriations – $12,000,000

In order to assure the same diagnostic, prescriptive and educational services to deaf-blind children in school year 1975-76 as provided in 1974, the Deaf-Blind Centers Program will provide the following:

1. Full-time educational services will be maintained for 2,600 children.
2. Diagnostic and educational assessment services to 700 new children.
3. Short-term and part-time educational services will be held level at approximately 700 children and possibly decrease as more children are phased out of this category into full-time educational service programs under local, state, and federal funds.
4. Counseling services will be maintained for 3,000 parents and a parent Home Correspondence Course will be distributed to an additional 1,000 families.
5. In-service training for 3,000 parents and professionals.
6. The National Registry of all deaf-blind persons will be maintained in cooperation with the National Center for Deaf-Blind Youths and Adults.
7. Technical assistance will continue to all deaf-blind projects funded under the Regional Centers.
8. Efforts to deinstitutionalize deaf-blind children from state hospitals and schools for the retarded will be maintained.
9. A third-party evaluation effort will be undertaken.
10. Support services to each deaf-blind project will be continued by the Regional Centers. These services include stimulation, initiation, and coordination of new service delivery systems; research; casefinding and screening; technical assistance; and in-service training activities.

TABLE I
GEOGRAPHICAL DISTRIBUTION OF DEAF-BLIND CHILDREN


Alaska – 28
Washington 108
Oregon 65
Idaho 18
Montana 35
Wyoming 18
North Dakota 16
South Dakota 54
Minnesota 80
Nebraska 47
Iowa 69
Wisconsin 25
Mich. 36
Illinois 135
Ind. 40
Ohio 36
Nevada 8
Utah 40
Colorado 76
Kansas 69
Missouri 83
Kentucky 25
W. Va. 19
Virginia 132
Calif. 686
Arizona 39
New Mexico 80
Oklahoma 106
Arkansas 49
Tenn. 62
N. Car. 108
S. Car. 57
Texas 394
La. 143
Miss. 77
Alabama 36
Georgia 95
Fla. 89
Maine 8
Vt. 7
New York 291
Pennsylvania 129
N.H. – 11
Mass. – 94
R.I. – 17
Conn. – 53
N.J. – 129
Md. – 85
Del. – 8
D.C. – 35
Puerto Rico – 46
Virgin Islands – 5
Guam – 3
Hawaii – 15
Trust Ter. – 1

TOTAL NO. OF CHILDREN: 4,414
(As of Nov. 1973)

TABLE II
CENTERS AND SERVICES FOR DEAF-BLIND CHILDREN
NUMBER OF DEAF-BLIND CHILDREN IN SERVICE PROGRAMS, 1974

NEW ENGLAND REGIONAL CENTERS	TOTAL	NO SERVICES	IN PROGRAM
CONNECTICUT	53	0	53
MAINE	8	0	8
MASSACHUSETTS*	94	17	77
NEW HAMPSHIRE	11	0	11
RHODE ISLAND	17	1	16
VERMONT	7	0	7
TOTAL	190	18 (9%)	172 (91%)

*Eight children not shown in their home state are residents at Perkins

MID-ATLANTIC (NORTH AND CARIBBEAN)	TOTAL	NO SERVICES	IN PROGRAM
DELAWARE	8	3	5
NEW JERSEY	129	6	123
NEW YORK	291	23	268
PENNSYLVANIA	129	15	114
PUERTO RICO	46	0	46
VIRGIN ISLANDS	5	0	5
TOTAL	608	47 (7.7%)	561 (92.3%)

MID-ATLANTIC REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
DISTRICT OF COLUMBIA	35	4	31
MARYLAND	85	18	67
NORTH CAROLINA	108	31	77
SOUTH CAROLINA	57	7	50
VIRGINIA	132	104	28
WEST VIRGINIA	19	6	13
TOTAL	436	170 (39%)	266 (61%)

SOUTHEASTERN REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
ALABAMA	36	5	31
FLORIDA	89	12	77
GEORGIA	95	39	56
KENTUCKY	25	5	20
MISSISSIPPI	77	19	58
TENNESSEE	62	16	46
TOTAL	384	96 (25%)	288 (75%)

MIDWEST REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
ILLINOIS	135	10	125
INDIANA	40	0	40
MICHIGAN	230	14	216
OHIO	36	0	36
WISCONSIN	25	0	25
TOTAL	466	24 (5.2%)	442 (94.8%)

CENTRAL REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
MINNESOTA	80	21	59
IOWA	69	7	62
MISSOURI	83	33	50
NORTH DAKOTA	16	2	14
SOUTH DAKOTA	54	12	42
TOTAL	302	75 (25%)	227 (75%)

TABLE II – *Continued*

SOUTH CENTRAL REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
ARKANSAS	49	4	45
LOUISIANA	143	27	116
OKLAHOMA	106	14	92
TEXAS	394	63	331
TOTAL	692	108 (15.6%)	584 (84.4%)

MOUNTAIN PLAINS REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
NEW MEXICO	80	0	80
WYOMING	18	0	18
COLORADO	76	2	74
KANSAS	69	0	69
UTAH	40	5	35
NEBRASKA	47	3	44
TOTAL	330	10 (3%)	320 (97%)

NORTHWEST REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
ALASKA	28	8	20
IDAHO	18	1	17
MONTANA	35	3	32
OREGON	65	9	56
WASHINGTON	108	40	68
TOTAL	254	61 (24%)	193 (76%)

SOUTHWESTERN REGIONAL CENTER	TOTAL	NO SERVICES	IN PROGRAM
CALIFORNIA	686	337	349
ARIZONA	39	0	39
GUAM	3	0	3
HAWAII	15	0	15
NEVADA	8	0	8
TRUST TERRITORIES	1	1	0
TOTAL	752	338 (44%)	414 (56%)

	TOTAL	NO SERVICES	IN PROGRAM
NEW ENGLAND REGIONAL CENTER	190	18	172
MID-ATLANTIC (NORTH AND CARIBBEAN)	608	47	561
MID-ATLANTIC REGIONAL CENTER	436	170	266
SOUTHEASTERN REGIONAL CENTER	384	96	288
MIDWEST REGIONAL CENTER	466	24	442
CENTRAL REGIONAL CENTER	302	75	227
SOUTH CENTRAL REGIONAL CENTER	692	108	584
MOUNTAIN PLAINS REGIONAL CENTER	330	10	320
NORTHWEST REGIONAL CENTER	254	61	193
SOUTHWESTERN REGIONAL CENTER	752	338	414
TOTAL	4,414	947 (21%)	3,467 (79%)

TABLE III
AGE DISTRIBUTION AND CHILDREN SERVED BY CENTERS AND SERVICES FOR DEAF-BLIND CHILDREN

CENTER	MASS.		N.Y.		N.C.		ALA.		MICH.		MINN.		TEXAS		COLO.		WASH.		CAL.				
REGION	1		2		3		4		5		6		7		8		9		10		Sub-Total		TOTAL
AGE	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	No Services	In Program	
0-2 yrs.	1	0	0	2	1	0	0	1	0	4	5	8	2	7	0	15	2	3	0	9	11	49	60
3-5 yrs.	4	7	3	39	10	21	0	31	3	38	11	16	10	72	1	56	8	27	4	54	54	361	415
6-8 yrs.	4	28	7	89	28	50	0	67	3	85	10	53	21	118	1	69	15	48	3	104	92	711	803
9-11 yrs.	0	85	19	272	44	102	0	171	5	148	15	61	32	170	2	80	5	56	5	166	127	1311	1,438
12-14 yrs.	0	18	2	48	20	35	0	27	0	34	9	27	13	54	2	47	7	28	1	41	54	359	413
15-17 yrs.	2	24	7	47	25	31	0	44	2	43	9	25	11	81	1	32	4	20	3	28	64	375	439
18-21 yrs.	6	14	6	27	17	23	0	25	3	40	7	25	12	54	0	16	17	7	4	12	72	243	315
21+ yrs.	1	4	2	22	4	4	0	9	0	39	9	12	2	6	0	2	3	4	0	0	21	102	123
Unknown Birthdate	0	0	1	15	21	0	0	9	8	11	0	0	5	14	3	3	0	0	0	0	38	52	90
Subtotal	18	180	47	561	170	266	0	384	24	442	75	227	108	576	10	320	61	193	20	414	533	3563	4,096
TOTAL	198		608		436		384		466		302		684		330		254		434		4,096		

TABLE IV

CENTERS AND SERVICES FOR DEAF-BLIND CHILDREN

CURRENT SERVICE PATTERN: FUNDS AND NUMBERS OF DEAF-BLIND CHILDREN SERVED

PROGRAM YEAR 1973-1974 APPROPRIATION $10,000,000

TITLE VI–C REGION	AMOUNT IN M	TOTAL NO. SERVED	FULL-TIME SCHOOL YEAR RES.	FULL-TIME SCHOOL YEAR DAY	PART-TIME SHORT-TERM RES.	PART-TIME SHORT-TERM DAY	LESS THAN 30 HRS/YEAR
Alabama	875	499	131	53	145	80	90
California	800	697	79	18	50	0	550
Colorado	1,302	308	117	40	30	21	100
Massachusetts	875	184	167	17	0	0	0
Michigan	979	379	95	76	15	0	193
Minnesota	535	274	144	20	0	110	0
New York	1,478	499	165	87	66	56	125
North Carolina	849	250	139	12	8	62	29
Texas (Callier)	1,133	256	94	74	0	30	58
Washington	847	196	128	67	0	1	0
Texas Ed. Agency	327	290	67	113	0	110	0
Subtotal		3,832	1,326	577	314	470	1,145
TOTAL	$10,000	3,832	1,903		784		1,145

TABLE V

SUPPLEMENTARY FACT SHEET

DEAF-BLIND CENTERS

CENTERS AND SERVICES FOR DEAF-BLIND CHILDREN

FISCAL YEAR	1972	1973	1974	1975
PROGRAM YEAR	1972-1973	1973-1974	1974-1975	1975-1976
APPROPRIATION	$7,500,000	$15,795,000	$14,055,000	$12,000,000
Center Developed	10	11*	10	10
Full-Time Educational Services	1,273	1,903	2,600	2,600
Short-term, part-time, education services (summer school, interim intensive care, assessment, and programs providing more than thirty hours/year service but not more than three days/week)	431	784	700	700
Diagnosis and Evaluation (Less than thirty hours per year)	642	1,145	700	700
Parent Counseling	1,800	3,000	3,000	3,000
In-service Training	400	1,200	3,000	3,000
Number of Deaf-Blind Children in United States as of March 1973		5,064		

LOCATION OF DEAF-BLIND CENTERS

1. Talladega, Alabama
2. Sacramento, California
3. Denver, Colorado
4. Watertown, Massachusetts
5. Lansing, Michigan
6. Bronx, New York
7. Raleigh, North Carolina
8. Dallas, Texas
9. Seattle, Washington
10. Austin, Texas (State Center)

*11. St. Paul, Minnesota
(Not Funded After Fiscal Year 1973)

TABLE VI
TOTAL GRANTS APPROVED REGIONAL DEAF-BLIND CENTERS FISCAL YEAR 1969-73

REGIONAL CENTER	PROGRAM YEAR 1969-1970 FISCAL YEAR 1969	PROGRAM YEAR 1970-1971 FISCAL YEAR 1970	PROGRAM YEAR 1971-1972 FISCAL YEAR 1971	PROGRAM YEAR 1972-1973 FISCAL YEAR 1972	PROGRAM YEAR 1973-1974 FISCAL YEAR 1973	PROGRAM YEAR 1974-1975 FISCAL YEAR 1974
ALABAMA	$ 150,250.00	$ 202,000.00	$ 300,000.00	$ 795,000.00	$ 875,000.00	$ 1,122,363.00
CALIFORNIA	189,000.00	337,760.00	677,000.00	975,000.00	800,000.00	2,005,000.00
COLORADO	36,260.00	250,000.00	450,000.00	800,000.00	1,302,000.00	2,019,228.00
MASSACHUSETTS	177,525.00	279,855.00	410,415.00	700,000.00	875,000.00	1,093,750.00
MICHIGAN	50,000.00	109,736.00	437,000.00	875,000.00	979,000.00	1,585,955.00
MINNESOTA	---------------	50,000.00	249,998.00	350,000.00	535,000.00	---------------
NEW YORK	189,000.00	280,000.00	460,000.00	830,000.00	1,478,000.00	2,050,000.00
NORTH CAROLINA	---------------	50,000.00	275,000.00	550,000.00	849,000.00	1,225,000.00
TEXAS (CALLIER)	51,039.00	290,000.00	790,587.00	975,000.00	1,132,726.00	1,380,697.00
WASHINGTON	156,926.00	150,649.00	450,000.00	650,000.00	847,000.00	1,155,548.00
TEXAS EDUCATIONAL AGENCY	---------------	---------------	---------------	---------------	327,274.00	417,459.00
TOTAL	$1,000,000.00	$2,000,000.00	$4,500,000.00	$7,500,000.00	$10,000,000.00	$14,055,000.00

The Silent Child and the Squeaking Wheel Syndrome

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History does not reveal the events that led to the sage's musing when he commented that "An ounce of prevention is worth a pound of cure." Were he to originate that proverb today, he might have in mind the countless children who are experiencing deformity, failure or defeat because of multisensory and/or other multihandicapping conditions. Unfortunately, agencies responsible for education and services for these persons are faced with "pounds" of cure for all handicaps, ranging from mild to serious.

This paper will establish a philosophical premise which might or might not be acceptable to state education agencies and the special education profession. Further, the paper will deal with general problems and include recommendations relating to the establishment of comprehensive programs for the deaf-blind. Finally, there will be a discussion of practical problems encountered by state education agencies and, hopefully, alternatives offered.

Philosophical Premise

State education agencies across the country are grappling with the problem which generally has not been regarded as their responsibility. The problem has often been compounded because professional educators and some state departments of education have not accepted the idea that seriously involved (multihandicapped) children are the responsibility of the public schools. On the other hand, the public's (parents) attitude borders on militancy, as evidenced by the tremendous amount of litigation presently matriculating through the courts.

The recent decision in the Rodriguez* case that citizens do not necessarily have a right to free public education has not negated states's responsibilities. Most state constitutions, if not all, clearly hold that respective citizens do in fact have that right. *The first premise is that all deaf-blind children do have a right to education. The second premise is that states do have a legal responsibility to insure that right.*

Professional special educators in the United States have not been basically responsive to their responsibility in implementing and maintaining the necessary programs for the seriously multihandicapped. The "squeaking wheel — grease-getting" philosophy, along with professional selectivity, has played a major role in the present ineffective delivery of services. The level of services continuum is from the "majority" to "minority" and "mild" to "severe". *The third premise is that "creaming" must cease in practice in responsible legal agencies and conceptually in the special education profession.*

One of the most serious problems is lack of research and experience in mass educational delivery for severely multihandicapped children, such as deaf-blind. Further, it is distressingly apparent that there is a sharp rise in numbers of children needing services. There is little said or done about causative factors such as drugs, the disease meningitis and the hundreds of "battered" children. The rubella epidemic and its subsequent attention gave impetus to the plight of affected children and their families. Nevertheless, hundreds of children are being excluded from programs because there is not enough collective "clout" to force their case.

Each of the previously mentioned variables dictates the necessity for a comprehensive compendium of programs and services. For purposes of this paper, it is suggested that deaf-blind function at four levels of potential which include:

1. independent living,
2. sheltered environment-community base,
3. dependent living-community base, and
4. dependent living-institution.

This means that basic education programs are needed at each level, in addition to support programs including medical, psychological, counseling, social work, and dental services.

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* San Antonio Independent School District v. Rodriguez (1973) U.S. Supreme Court.

Prevention

Prevention or subsequent elimination of the conditions leading to multisensory handicaps have received minimal attention. It is true that rubella inoculation is available for expectant mothers and that information campaigns are mounted. Beyond this, however, funds and program emphasis are lacking. For example, meningitis has not been cured—only treated. "Battered" children by the hundreds enter hospitals and often the responsible parents cannot be prosecuted.

Preventive programs which would include a necessity for research funds for meningitis, drug effect studies and continued rubella study are needed. Public information programs, complete counseling services for whatever services are needed should be provided to make responsible persons aware of the tremendous waste of children brought about by ignorance and inhumanity.

Priorities

Priorities should not be set in the area of program emphasis. As important as prevention is, it cannot be a priority ranking over the need for early intervention. Naturally, with cripplers such as congenital rubella syndrome and meningitis, the medical community must be vitally involved. That profession will be first involved and most likely continue to be involved throughout the lives of those affected. Theirs is a responsibility of early diagnosis and training. Training, of course, often involves extended hospitalization and surgical intervention. Education, of necessity, must enter the picture immediately; otherwise, the child is almost surely doomed to level three or four and complete dependency on either parents, society or both. There should be a catalytic effect in that all agencies be immediately involved. Counseling and social services for the parents and subsequently for the child are imperative.

Classification and Diagnosis

There is a further problem which may not be resolved. Classification and diagnosis of handicapped children, youth and adults by any discipline have been difficult and often confusing. Education has long argued that medical classification does not lend itself to the solution of educational problems. In effect, classification has become mixed with diagnosis and subsequently with prescription or remediation with forced solutions.

A classification system is needed which lends itself to all disciplines involved in programs and services for deaf-blind and their families. The system should allow those needing the programs and services to develop to their fullest potential and not force them to fit the system.

Parental Support

Perhaps it is digression to make mention of the needs of parents. If so, the readers may regard it as a bias. Parents need much in the way of guidance, counseling and general support in these early days of their distress. They need support in understanding the child's handicapping conditions; they need to know where they can turn for assistance along the way; they need to know the programs and services available to them; they need support in understanding the many new problems they face regarding child rearing; for example, what they, the parents, can do toward teaching eating skills, toileting skills, and general self-care skills when these milestones are not reached in the traditional way — what they can do to enhance the acquisition of communication skills. The parents need assistance along the way in all areas of development and understanding.

In addition, parents often need support in thinking through and coping with their guilt feelings when they realize they have brought a handicapped child into the world. Theirs is the question, "Why?" Oftentimes they feel this child is their "cross to bear" for some wrong they might have committed. They need support in developing a healthy relationship with the child; in coping with well-meaning, advice-giving friends and relatives; and often support is needed in developing handicapped child-sibling relationships. Then there is the associated guilt which arises somewhat later as parents wrestle with the question of institutional placement — whether it be for education, training or custodial care.

Practical Problems

Persons functioning in the role of state directors of special education are faced with a multiplicity of problems. In addition, they must be impartial and unbiased in attempting to assist in the provision of programs for all handicapped children. Many factors have impacted on the current philosophies and levels of educational delivery in the states and territories. For example, state directors as a group do not function at the decision-making level. This is an important factor in attempting to command necessary state dollars to implement and maintain programs.

State directors have felt the impact of the "squeaking wheel — grease getting" syndrome and the "creaming" effect. As noted earlier in this paper, it has not been the philosophy of public education to assume responsibility for very seriously involved children, such as deaf-blind. Further, as noted previously, the special education profession has given its emphasis to the more mildly handicapped and has demonstrated its success by dealing with children for whom success is more predictable.

Alternatives

The variables noted above dictate the need for legislation which mandates service delivery to severely multihandicapped individuals. Further, the federal government must intervene. It is virtually impossible to provide programs which are tremendously expensive (even though the investment is small) to the low incidence severely handicapped. This paper strongly supports the position that regional programs should be funded with federal dollars and with interstate control measures.

Curriculum Changes

Curriculum changes will be involved in providing service to these children, which affect teacher preparation programs in the United States. A massive recruitment effort must be initiated to provide a whole new population of teachers who can be trained for specific needs as evidenced by deaf-blind children. In addition, competencies of teachers presently in the field must be upgraded. Training programs should include paraprofessionals, teacher aides, and houseparents. Traditional course offerings must be interspersed with new and innovative methods of working with children as successes from the field point the way to better and more efficient ways of serving this population.

Cost

A very basic question continually asked today is "Can we afford it?" We rarely stop and ask "Can we not afford it?" Education is nearly always talked about in terms of cost—rarely as a benefit or investment. Only recently have programs for handicapped children been discussed other than in the emotional appeal sense or as a constitutional right. New data suggests that programs for deaf-blind, even as expensive as they obviously are, become an investment and not a burden. There are estimates of the cash value of a human unit to society which range from $150,000 to $300,000. The cost to make this unit productive is less than half the stated value. This establishes the investment concept despite how cold the above statements might appear. Put simply, comprehensive programs and services for deaf-blind would ultimately be an investment—not a cost.

It is evident that providing complete services for the deaf-blind or the multihandicapped population is no simple task. It requires the unstinting efforts of many individuals, groups, and agencies. It requires the cooperation and involvement of all concerned. The more concerned, the more likely we are to adequately cope with the problem of providing services to meet collective needs of seriously involved persons.

Education encompasses many phases for many individuals. It must begin early; it must be continuous; it must be designed to fit the needs of each individual; it must be coordinated by the state agency assigned the responsibility for providing education for its population. Until the handicapped individual becomes self-sufficient and self-supporting, tremendous expense is involved. The duration of this period could be from birth until death, as many deaf-blind will not reach a level of self-sufficiency. Must this expense be borne by the families alone? This and many other questions that are constantly being raised means that we must try and predict the future. 1980 IS NOW!

Recommendations

In summary, the following recommendations need immediate consideration in carrying out plans to serve the deaf-blind population.

1. Needs assessments, if not made, must be made and they must be constantly revised and updated.
2. Prevocational programs must be established to insure transfer from special classroom programs to vocational training programs.
3. Vocational training facilities must be either modified or developed so that deaf-blind youth can receive and benefit from training.
4. Special federal legislation must be enacted to establish employment agencies for the deaf-blind; e.g., legislation comparable to the Randolph-Sheppard Act of 1936, P.L. 75-732, which established vending stands for the blind.
5. Alternative living arrangements must be developed for the adolescent and young adult population, such as group homes and apartment living.
6. To insure family stability, relief should be provided (social workers, volunteers, "baby-sitters") to enable parents, guardians, etc., to have release time from the constant care of the deaf-blind.
7. Community services which include recreation and social life should be sought, reinforced and/or developed.
8. A communications system must be developed for all levels of individuals, particularly the lower functioning level. If we keep these children alive, we have an obligation to help them live above the animal level.

We must never be guilty of denying "the least of my little ones" the opportunity to *live.* One never knows when or where there lies or sits a Robert Smithdas who can write and feel like this —

SHARED BEAUTY

I cannot see a rainbow's glory spread
Across a rain-washed sky when storm is over;
Nor can I see or hear the birds that cry
Their songs among the clouds,
or through bright clover.
You tell me that the night is full of stars,
And how the winds and waters sing and flow;
And in my heart I wish that I could share
With you this beauty that I cannot know.
I only know that when I touch a flower,
Or feel the sun and wind upon my face,
Or hold your hand in mine, there is a brightness
Within my soul that words can never trace.
I call it Life, and laugh with its delight,
Though life itself be out of sound and sight.

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National Center for Deaf-Blind
Youth and Adults
New Hyde Park, New York

Current Services and Plans for Expansion

Services for the Handicapped – The Road Less Travelled

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Department of Health, Education, and Welfare

Thank you for the opportunity to speak before you today as a participant in this conference. I bring you the best wishes and greetings from Dr. Ed Martin, the Deputy Commissioner of Education for the Handicapped. Dr. Martin had been planning to attend this meeting and was looking forward to it. Because of unforeseen circumstances which delayed the hearing on the Education Budget before the U.S. Senate Appropriations Committee, Dr. Martin will be unable to attend. The progress and development of Centers and Services for Deaf-Blind Children has been and continues to be of particular interest to me. Being here today reminds me of a similar moment some years ago when the federal government first accepted responsibility for the education of deaf-blind children with the signing of P.L. 91-230, the Education of the Handicapped Act. We have come a long way in special education since that time, particularly in the deaf-blind program. Our catalytic input from the federal level will have either stimulated or actually provided full time educational services to more than 2,600 deaf-blind children in 1974, a sizeable growth from the sixty plus children who were receiving services at the inception of the program. Our appropriations have grown from one million dollars in fiscal year 1969 to fourteen million dollars in fiscal year 1974. The number of available programs has also grown from a very few to well over a hundred. Despite the record growth and development in this program over the past six years, I have had difficulty in organizing my thoughts prior to meeting with you. While drafting my paper, I chanced to read Robert Frost's *The Road Not Taken.* In a few lines, he sums up where, I believe, we have been and where we are going in provision of services to this group of very severely handicapped children.

> *Two roads diverged in a wood,*
> *and I –*
> *I took the one less travelled by,*
> *And that has made all the difference.*

Crossroads

Just as we were at a crossroads in 1968 when we first embarked on an effort to provide educational services to each and every deaf-blind child, so, too, are we now at a similar crossroads with the present deaf-blind strategy. Where do we go from here? Is it sufficient for us to allow a good program to simmer? Or is it not our role at the federal level to provide sufficient stimulus to make a good thing better? Because of the very nature of this severely handicapped population, with its considerable need for services we feel it is incumbent upon us not only to stimluate improvement, but also to avoid, at all costs, any maintenance of a status quo provision of services. It is a road not often travelled in the federal government. It is a road which we recognize to be full of pitfalls. Inherent in any close scrutiny of an existing program is the risk of losses, as well as the reward of gains. We feel that the potential benefits to these children far outweigh the risks involved in such an effort. That is why this conference is being held. That is why the Bureau has embarked on an ambitious six-month project to improve and refine the deaf-blind strategy on a national basis. The time has come for those of us at the federal, state and local levels as well as other private and public workers to begin to focus on the need for a continuum of services for these children as they grow into adulthood. The time has come for us to obtain a clear picture of whom we are serving, where we are serving them, and with what resources we are serving these children. None of these efforts will be easily accomplished. Nor do we anticipate a smooth road on which to travel quickly. But they will be done.

Committment

To improve and refine the deaf-blind services and strategies will require two things – communication and evaluation. Ed Lowell has brought us here today to communicate the need for a continuum of services; to impress upon us all the necessity for evaluation of our efforts in this area. The Bureau has informed many of you recently of a joint project, and in so doing has elicited your support and cooperation in a BEH, Management Analysis Center, and project and program personnel attempt to conduct a rather simple audit of services to deaf-blind children both now and in the future. It is an effort to identify clearly what it is we are doing for these children on a comparable basis across the country; it is an effort to focus on our strength as well as our weaknesses in order to provide the best services possible. Taking a long, hard look at ourselves, and asking you people to do the same requires a willing and total commitment — a commitment to the 5,000 plus deaf-blind children whom our efforts are designed to benefit.

Progress

The former educator, James Conant, used to say that "A turtle only makes progress when he sticks his neck out." It is progress which we hope to make in the provision of services to these children over the next three to five years. It is progress we hope to achieve in assertion of our role at the federal level as the Bureau with primary responsibility for the provision and coordination of services for this group of severely handicapped children. Yet cognizant we are of the keystone in our efforts to build and maintain a network of sufficient services. And that keystone is you — *the people* — who actually intervene in the life of a deaf-blind child in an effort to move that child a little closer to a more normal life style.

"Why," some of you might ask, "are we just now embarking on this effort at the Federal level?" We have been moving in this direction for the past year and a half. Recent events and directions have merely quickened the process. As our focus begins to sharpen with respect to specific programs such as the one for deaf-blind children, we are at the same time beginning to enlarge the focal plane to include more and more of the severely handicapped child population. Evidence of this effort can be seen in our recently released "Request for Proposals for Establishment of Programs for the Severely Handicapped"; in our efforts to stimulate curriculum development and teacher training in the area of the severely handicapped; in our proposed legislative consolidation which calls for an identified category of "Services for the Severely Handicapped"; and in our recent Bureau of Education for the Handicapped reorganization in which we gathered together programs for the severely handicapped in the Special Services Branch within the new Division of State Assistance.

Evaluation

For any of these efforts ultimately to be effective and meaningful, change agents will require great communication — to identify the high and low spots in the road through the assistance of others; evaluation — to identify and mark the soft spots which might otherwise have bogged us down and coordination — to assure safe passage. As I have pointed out before, it is a road not often travelled by the federal government. This is the first time we at BEH have ever embarked on such an ambitious project, with such an atypical approach. But if we are successful, then it will have made all the difference to the multitude of deaf-blind children, in fact to all children — because of the way in which our lives are intertwined — who look to us to make their lives more meaningful and more productive. And if that happens then all the toil and trouble will have been worth it. I believe that now we are once again at the point where the roads diverge. We feel that the next five months of analysis and this kind of conference will provide us with an accurate answer to that question.

The Rehabilitation Services Administration's Role in the Rehabilitation of Deaf-Blind Persons

D. C. MacFarland, Ph. D.

Director
Office for the Blind and Visually Handicapped
Rehabilitation Services Administration

I shall try in developing this paper not to repeat much of the same ground covered by the representative from the National Center for Deaf-Blind Youths and Adults. It will be impossible to avoid some repetition, however, since much of our program is tied closely to center activities, and, of course, we did not exchange viewpoints in the preparation of materials for this meeting.

Role of Rehabilitation Services Administration

The Rehabilitation Services Administration and its predecessors have been interested in the problems of deaf-blind persons since the late fifties, and provided the support which eventually led to the establishment of the Anne Sullivan Macy Service Center. This center was initiated to serve as a demonstration project for fifteen states east of the Mississippi. Eventually, the services were extended far beyond this geographic area in order to partially meet the need that was extant at that time. The results of several years of operation of the Anne Sullivan Macy Center clearly demonstrated the need for national servic and legislation that would make such a service possible.

When the original legislation was proposed, it was contemplated to cover both children and adults. There was a great deal of discussion which logically led to the establishment of complementary programs. The Office of Education was charged with the responsibility for providing adequate educational opportunities for deaf-blind children during their years spent in elementary and secondary schools.

Role of the National Center

The National Center was designed to provide vocational and rehabilitative services for the adult population, many of whom were disabled after they had completed public school. The title of the center, which stemmed from legislation, deliberately incorporated the word "youths" in order to provide an easy transition from the academic school program to one that was vocationally oriented. It would not be practical nor desirable for the center to accept children of school age except where the training was specifically oriented toward a vocational goal. Except where otherwise indicated because of extraordinary circumstances, the lower age limit for enrollment at the center should be set at eighteen or above in order to give the child full advantage of the academic schooling to which he is entitled.

Annual budgeting and administration should continue in the pertinent sections of the Health, Education, and Welfare budget:

1. support by the Office of Education for deaf-blind children, and
2. support as part of the Rehabilitation Act, with appropriate training focused on "youths and adults."

As the program expands to include training in rehabilitation facilities throughout the country, money specifically earmarked for the handicapped (ten percent in the Vocational Education Act, 90-576) can be tapped at the state level for financing equipment and other resources that will be necessary. Center staff will collaborate with the Office of Education and their regional centers for children on research development and utilization.

Legislation and Funding

As you all know, legislation was passed separating the two programs. In accordance with legislative requirements, proposals for operating the Center for Deaf-Blind Youths and Adults were solicited and submitted to a panel, and the Industrial Home for the Blind was chosen to operate the center. Although a contract was signed in June 1969, the center continued to be funded from our Research and Demonstrations budget. The original grant for constructing the center was approximately $2,500,000.00. At that time, it was contemplated that the center be located on a fairly small piece of property which would have seriously hampered the kinds of model services that should be offered. Fortunately, before a permanent site was selected, a piece of valuable surplus property became available at Sands Point, Long Island. After a great deal of negotiation, twenty-five acres were deeded to the Industrial Home for the Blind to plan the center on a much broader scale than had been dreamed of originally. Obviously, to construct the facility at Sands Point would take a considerable amount of money in addition to the $2,500,000.00 originally allocated. Although no one seemed opposed to increasing construction funds, for a number of reasons which are of no consequence in this conference, it took an inordinate amount of time before the final supplementary grant of $5,000,000.00 was awarded on October 18, 1973.

As you will undoubtedly learn from Dr. Salmon, the contract was signed in December and construction is now under way. The facility should be ready for occupancy in the fall of 1975. Much of the negotiations for staffing can take place before that date. However, it is obvious that it will still take some time before the center will reach its peak production in its new location.

While the center now stands as a separate entity with a contract with the Social and Rehabilitation Services Administration, with its own separate appropriations listed in the Rehabilitation Services Administration's budget, it seemed quite logical at first to continue it as a Research and Demonstration grant, since the major of its three functions was considered to be research. As the plans for the center evolved, however, it became apparent that while the center would have three responsibilities—each important and interrelated—the major problem for some time to come would be service. Therefore, the contract was officially expanded on December 27, 1973 tying its operations more closely to the Rehabilitation Services Administration.

Programs

The center would be responsible for the following programs:

1. Providing in depth rehabilitation services to at least one hundred of the most difficult deaf-blind clients annually. I am sure that Dr. Salmon will describe some of the cases we have in mind.
2. The center will offer training programs—both long and short term. The short-term training programs will offer courses to students who can work in local areas in order to provide communications and other links between the deaf-blind person and the community. These courses will be especially important to vocational rehabilitation counselors in public and private agencies. A limited number of students will be enrolled for long-term training so that they can eventually become valuable staff members in state and private rehabilitation facilities throughout the country. It is our plan to develop special components in many of the centers so that most of the adult deaf-blind population who are not in need of the long-term in depth services required at the center headquarters can be provided necessary services in their own communities. From the Rehabilitation Services Administration's standpoint, this is a major thrust that we hope to build in place as soon as possible in order to treat the majority of the clients throughout the country.

   When the program is in full operation, we envision one hundred plus clients at the center annually and at least four hundred in the more sophisticated rehabilitation facilities that we now have in operation. In addition to being a practical method for providing quality services, it also tends to assure interest, participation and support of our state agencies. This cannot be done without adequate training. We are not interested in developing mere lip-service to the deaf-blind citizens of our nation—they have been receiving this service too long.

   Naturally, a strong link will be developed between the rehabilitation facilities with special components for the deaf-blind and the national headquarters at Sands Point so that special facilities interested in incorporating units for the deaf-blind will be assured that professional assistance is available when necessary.
3. The third function of the center is to conduct intensive research on new hardware for deaf-blind persons, expansion and development of new devices and techniques to remove or reduce the complex problems of deaf-blindness. It should be understood that such research will be conducted in conjunction with universities, interested industries, and certainly the regional centers for the education of deaf-blind children.

The center, when it is in full operation, will provide a marvelous laboratory for determining the usefulness of research products. It will constitute one of the few places in the world where you will have at any given time, fifty or more deaf-blind persons which will make possible the pooling and testing of ideas, a greatly accelerated process for separating the "wheat from the chaff." Even in the temporary headquarters, there are already some rather exciting communications devices which have been designed.

Future Plans

Additional future plans will depend in large measure on the kind of basic research we are able to develop. I was very pleased to learn at the last advisory committee meeting of the National Center that the regional center programs have asked the National Center to compile and update the demographic information on both children and adults. This is extremely important for any plans that we may develop. We must have firm knowledge of how many deaf-blind persons there are in the country and, what is more important, an assessment of their needs. The closer the linkage system, the quicker we can determine how much help we can expect from research.

How effective, for example, are the rubella vaccines? What are the best methods for administering the vaccines? What other conditions are basic causal factors for deaf-blindness that should be studied? In essence, the question I am asking is: Can we develop reliable predictors on which to base service needs? I have been reviewing the information contained in the bulletin published by the Center for Disease Control in Atlanta concerning rubella and the congenital rubella syndromes.

Although the information compiled thus far is by no means conclusive and the center is cautious in making definitive statements, it is apparent that there has been a marked decrease in rubella since they have been gathering data in 1966. The figures for the first quarter 1974 are only slightly less than one-third the number shown for the corresponding period in 1973 and, approximately twenty-five percent of the median taken for the same period during the past five years.

Although a great deal more of data gathering is required, it would appear that more than 45,000,000 vaccinations provided in the United States since the beginning of the program has had a very measurable effect and it would appear that we can continue to expect a sharp decline in rubella cases and the consequent results on children whose mothers are infected during the first trimester of pregnancy.

Although it is obvious that we have a long way to go, we have made rapid progress in the last several years. It is my belief that working together we will meet the needs and consequently the challenges of 1980, and plans that reach far beyond that date. We cannot do this, however, by working in a vacuum or in competition with each other. It can only be accomplished through a teamwork approach, sharing each other's successes and failures. It is indeed too bad that it took a tragedy like the epidemic of 1964 and 1965 to get us started.

On the brighter side of the coin, however, it is clear that we are a people that work best under pressure. It is avowed by authority that we are tripling our scientific knowledge every ten years. We have placed men on the moon and taken millions of photographs of the planets that coexist in our solar system. This is very exciting progress, but there are other pictures which we much concentrate on in the future if we are to become the nation that our founding fathers dreamed for us. It is the small but tough problems right at our doorstep that defy solution. If we can apply half the energy, ingenious inventive skill, and hard work that were expended in getting to the moon, we can certainly help our deaf-blind partners in society achieve the dignity and self-reliance that they deserve. 1980 IS NOW, but it's not enough. We must compress into this effort centuries of neglect so that in our lifetime the wealth and privileges that are ours today will be available to all tomorrow.

The Georgia Program for the Deaf Blind

Herbert D. Nash

Director
Special Education Program
State Department of Education
State of Georgia

Foreword

Effective programming and planning to combat multiple handicaps require a basic understanding and an awareness of the broad scope and nature of the problem. In recent years, there has been a growing awareness of the problems involved in the differential diagnosis, classification, education, training and habilitation of children with multiple disabilities.

Introduction

The Georgia Program for the Deaf-Blind offers three broad areas of service to multihandicapped children from Georgia. An evaluation component is provided on a nationwide basis for children twelve years of age and younger who are considered deaf-blind and on a statewide basis for those who have at least one sensory impairment in addition to other handicapping conditions. This component provides psychological, educational, social and medical assessments; recommendations for home training or educational placement and parental counseling. Children being evaluated are residents of Elks Aidmore Hospital for approximately two to three weeks. Each child evaluated from the state is followed by social work services until appropriate placement is accomplished.

The second aspect of the program is an educational component which provides two classroom units for multisensory impaired children from the metropolitan Atlanta area. These children live at home and attend classes on a day basis. The prime objective of this component is to develop academic and social skills commensurate with the child's ability. Some of these children will progress to such an extent that they can enter more traditional educational programs.

The third aspect of the program is a residential educational component. Deaf-blind children are accepted into this program from throughout the state. The prime objective of this component is to develop, in a residential setting, academic, social and community living skills commensurate with the child's ability.

The Georgia Program for Deaf-Blind Children is funded by the State Department of Education, DeKalb County Board of Education, Elks Aidmore Hospital, Title I and Title VI-B ESEA and the Southeast Regional Center for Deaf-Blind Children (Title VI-C ESEA).

Since its inception in 1969 the Georgia Program for the Deaf-Blind has had as its major goal appropriate and comprehensive programs in the state. Diagnostic and educational evaluation services have been developed, day school classes have been initiated to serve deaf-blind children in the metropolitan Atlanta area, a residential program for deaf-blind children is in operation at Georgia Academy for the Blind and placement has been found for 75% of the children who have been referred for services. Beginning in fiscal year 1973, diagnostic and educational evaluation services have been extended to qualifying deaf-blind children from the southeast region.

The Georgia Program was planned and developed in three phases. Phase I and Phase II have been implemented and are in full operation.

History

PHASE I.

The first phase had five basic aspects:

1. *Initial statewide screening and follow-up,* carried out by the Georgia Center for the Multihandicapped (Deaf-Blind) in cooperation with:

   Georgia Department of Public Health
   Georgia Department of Education
   Local Education and Health Agencies
   Public and Private Hospitals and Community Agencies
   Coordinator, Southeast Regional Center for Deaf-Blind

2. *Identification and referral of children.* Two hundred eighteen children have been referred for service; 104 have benefited from long-term evaluation at the Georgia Center for Multihandicapped. Counseling and referral to more appropriate programs have been given to those children determined to be ineligible for evaluation at the Georgia Center. All deaf-blind persons in Georgia who were twelve years of age or older were referred to the National Center for Deaf-Blind Youths and Adults. Some older deaf-blind children have been placed in regional centers. At this writing 27 additional youngsters are in the process of evaluation or placement. Seventeen more are on the waiting list.

3. *The initiation of community services.* The Georgia Center has stimulated and directly influenced program development for deaf-blind and multihandicapped children. A growing number of public and private schools serve multisensory impaired children. The Atlanta Area School for the Deaf (a state school), the Georgia School for the Deaf at Cave Spring and the Georgia Academy for the Blind are accepting children who are deaf-blind, deaf and/or blind with concomitant disabilities in regular programs. The Georgia Department of Education Consultant for the Multihandicapped is working to develop programs for deaf-blind children in other parts of the state.

4. *Development of a state-supported residential program.* At the Georgia Academy for the Blind, specifically for severely involved deaf-blind children who function at a low developmental level. Seventeen children are presently enrolled with expansion planned to serve twenty children in fiscal year 1974. Future plans call for a residential program to accommodate seventy-five to eighty severely involved multihandicapped children.

5. *State plan for continuous programming for deaf-blind children.* Georgia's mandatory legislation (H.B. 453) requires provision of full services for all exceptional children by 1976. Each local school system has developed comprehensive program planning budgeting systems for accomplishing this goal. These plans give evidence of the intent of the school system to meet the needs of the more severely involved as well as those who are moderately handicapped. The State Plan for Deaf-Blind Children is continuously evaluated in terms of current needs.

PHASE II.

Phase II was directed to implementation of services outlined in Phase I. A smoothly functioning state program serves the state's deaf-blind children. For each child served the process includes:

1. Complete medical assessment, consisting of:
    - Pediatric examination
    - Neurological examination
    - Ophthalmological examination
    - Audiological examination
    - Physiotheraphy and other evaluations as needed.
2. Education evaluation includes:
    - Psychological evaluation
    - Visual assessment and stimulation of function
    - Auditory assessment and training of function
    - Motor assessment and development of motor skills
    - Language assessment and training in receptive and expressive language
    - Recommendation of primary learning modalities
    - Recommendation of placement or home training
3. Placement in appropriate educational programs.
4. Follow-up services until child is appropriately placed.

The implementation of the Georgia Program has been made possible through the positive power of human resources combined with federal, state and local funds for deaf-blind and handicapped children. The tremendous development which has taken place in the Georgia program has been aided greatly be the financial and consultative assistance of the Southeast Regional Center for Deaf-Blind Children.

PHASE III.

The third phase is directed toward the expansion and refinement of services to deaf-blind children in Georgia and the Southeast Region. It represents an out reach program to extend the influence of the Georgia Program for the Deaf-Blind.

1. Increase capacity of the residential program for more severely involved deaf-blind children at the Georgia Academy for the Blind. More children will be served; more adequate services will be provided.
2. Expand individual follow-up services.
3. Expand parent education, home training and community services to parents of very young deaf-blind children and children awaiting evaluation and placement.
4. Develop and field test a curriculum guide which will provide a sequential approach to all phases of development of deaf-blind children for use by parents and teachers.
5. Encourage centralization of institutional programs for deaf-blind students.
6. Provide in-service education to educational, consultative and child care personnel of Georgia Program.

Chronology

The magnitude of the drastic rise of children with multisensory handicaps, especially those children who were victims of the 1964-65 rubella epidemic, placed a great responsibility upo[illegible]e state of Georgia to effectively meet the needs of these children. A series of meetings designed to gain information and to elicit involvement of appropriate agencies was held in 1967 and 1968. In October 1968, a general meeting was called by the Special Education Program of the State Department of Education to present information that had been gathered to date and to begin developing plans for the habilitation of multisensory impaired children.

Various agencies, including state education and health departments, state residential schools for the handicapped, national and private agencies and private citizens, have functioned on a high level of cooperation to provide for services, facilities, personnel and funding sources to initiate programs for deaf-blind children.

A brief summary of subsequent activities in the development of services for deaf-blind children follows.

FALL OF 1968

Members of the State Department of Education and the State Department of Public Health began a check of hospitals, agencies, physicians, etc., to attempt to locate deaf-blind children and to begin compiling information.

Attempts were made to locate a facility for a diagnostic and evaluation center for deaf-blind children. Elks Aidmore Hospital in Atlanta, a comprehensive hospital care program for handicapped children, was offered and accepted.

FALL OF 1968 THROUGH SPRING OF 1969

Outside consultation was obtained as plans were being developed for statewide services. Included in the consultants were Louis Z. Cooper, M.D., Department of Pediatrics, NYU Medical Center; Dr. Donald Calvert, Bureau of Education for the Handicapped, U.S. Office of Education; Dr. W. Scott Curtis, Syracuse University, Project for Deaf-Blind Children; Dr. Verna Hart, Coordinator of Training Programs for Multihandicapped and Deaf-Blind Children, Peabody College; Miss Pauline Moor, Program Specialist in Early Education, American Foundation for the Blind; Mrs. Prudence B. Walsh, Teacher of Deaf-Blind, California Public Schools.

Representatives of the State Department of Education, State Department of Public Health, Georgia State University, and others attended meetings in Nashville, Tennessee and Birmingham, Alabama, with representatives from Florida, Alabama, Tennessee, Mississippi and the U.S. Office of Education to consider recent legislation for Regional Centers for Deaf-Blind Children. The states were encouraged to write a cooperative project to serve all five states, incorporating their individual attempts into one regional program.

SPRING OF 1969

Representatives of the State Department of Education, Aidmore Hospital, Georgia Academy for the Blind and DeKalb County School System visited existing programs for deaf-blind children in order to learn more about services for these children. The deaf-blind programs at Perkins School for the Blind in Massachusetts, New York Institute for the Blind, Rubella Birth Defects Clinic, Bellevue Hospital in New York and Callier Speech and Hearing Center in Texas were a few of the programs visited.

Projects were written to utilize efforts and funds from various agencies to provide coordinated services for deaf-blind children. State, federal and local education money was projected as well as funds from private sources.

A cooperative workshop, sponsored by agencies and organizations in the southeast and planned by Georgia Department of Education, was conducted in Atlanta. This conference, "The Visually Handicapped Child Who Functions on a Retarded Level," had a strong emphasis on the deaf-blind child.

SUMMER OF 1969

The Georgia Academy for the Blind conducted a six-week day program for six deaf-blind children in the Macon area.

The Georgia School for the Deaf offered a six-week parent-pupil institute to attempt to provide information and counseling to the parents of young hearing impaired children. A large portion of these children were rubella youngsters.

Representatives of the Georgia Department of Education, the Georgia Department of Public Health and Elks Aidmore Hospital attended the organizational meeting in St. Augustine, Florida, of the Southeast Regional Center for Deaf-Blind Children. In August of 1969, Jack P. Nix, State Superintendent of Schools, officially committed Georgia to participate in the center.

FALL OF 1969

The Georgia Center for Multihandicapped Deaf-Blind was officially begun for a four-month period of planning. The director and professional educational staff were employed to further develop the plans for the center.

A two-day in-service program was conducted by the Southeast Regional Center for Deaf-Blind Children.

JANUARY OF 1970

The first group of deaf-blind children was accepted into the Georgia Center for evaluation. Since this time, the center has been in constant operation and has evaluated forty-five youngsters.

SPRING OF 1970

The Georgia Center for Multihandicapped Deaf-Blind sponsored a 45 hour in-service program for teachers and selected personnel working with deaf-blind children. National authorities in the education and training of deaf-blind children conducted this course. This course carried five quarter hours college credit.

The Georgia Academy for the Blind, in response to the great need for a residential program for certain deaf-blind children, began remodeling a portion of the partially vacant Shurling Campus of the Academy for the Blind for a program for deaf-blind children.

SUMMER OF 1970

The Georgia Academy for the Blind opened its residential program for deaf-blind children with seven children who had been evaluated at the Georgia Center for Multihandicapped Deaf-Blind and found to be in need of a residential program.

The Georgia School for the Deaf operated a second parent-pupil institute for 130 hearing impaired children and their parents. Approximately 70 of the children involved in the program were known to be handicapped due to maternal rubella. The emphases of the program were to familiarize the parents with ways to assist their children and to give the school staff the opportunity to evaluate the youngsters and orient prospective pupils to the residential program.

FALL OF 1970

The residential program for deaf-blind children at the Georgia Academy for the Blind was expanded to include ten youngsters.

The Georgia School for the Deaf expanded their program to include most of the youngsters referred by differential scheduling and maximum utilization of all resources including staff and facilities.

Construction of the first phase of a day school for the deaf in metropolitan Atlanta was begun through funds appropriated by the 1970 Georgia General Assembly. The first phase, a program of infant training, early childhood education and primary school, will be opened in 1972 for 175 hearing impaired children, including deaf children with multiple disabilities. The second and third phase, an intermediate and secondary school program respectively, will follow in the near future to insure a comprehensive educational program.

Various Georgia school systems and private schools have accepted the challenge of educating deaf-blind children in locally operated programs when existing programs in these systems have been found to be appropriate for individual children. Approximately fifteen such youngsters are enrolled in these programs.

SCHOOL YEAR 1971-72

The evaluation of children was integrated into the day class units. In doing this, one staff was utilized for both components. Initially this procedure functioned satisfactorily; however, toward the end of the year it was difficult for the evaluation children to adjust to a group who had been in a school situation. The gap in experience was too great. One of the major recommendations for the 1972-73 school year was a separation of the two components necessitating the employment of additional staff.

Traditional methods and equipment in audiological testing did not always produce the most accurate results. Upon the recommendation of the audiologist, the Masden Impedence Bridge equipment was purchased for her use in testing children. This equipment has proven of invaluable assistance in assessing hearing and other communication disorders of multihandicapped children.

Application and intake forms were updated by the staff and an information booklet was developed for the use of parents whose children are being evaluated in an effort to answer their questions and provide reassurance.

DAY•CLASS PROGRAM

In September 1971, two self-contained classroom units were begun for a total of up to twelve multisensory handicapped children from the metropolitan Atlanta area who were not accepted into existing programs because of their dual sensory impairments. The units were located in existing facilities of Elks Aidmore Hospital. Equipment and supplies were acquired to supplement those previously available through the evaluation component. Techniques appropriate for teaching the multisensory impaired were employed, including development of a communications system utilizing signing, gesture and oral communication were appropriate.

Behavioral objectives were established for each child in these classes. Daily records were kept on each child from which monthly behavioral summaries were written. Continued assessment was made to determine if behavioral objectives were being met and if they needed upgrading. Videotaping equipment was utilized to record progress of the children in these classes.

A speech therapist was made available through DeKalb County Program for Exceptional Children. She conducted 30 minute individual sessions twice a week for two children. Progress was noted in both children.

Audiological assessment was provided for those children who indicated need for retesting.

The primary objective of the day classes is to bring these children to the level of development and skill that they need to be integrated into appropriate and existing special education classes. Of the twelve children originally enrolled, three have made sufficient progress to transfer into more traditional special education programs.

Parent Training

Parents were encouraged to be involved as much as possible. They attended a conference once each quarter with their child's teacher. Three evening parent meetings held at the center were well attended and included instruction in total communication and open discussions of home problems of handicapped children. A newsletter was sent to all parents on a regular basis to keep families informed of class activities.

Summer Program

A summer program was devised to include language practice sessions, informal activities in art, music, motor and rhythm development. Also included during this session was a three-day overnight camping experience at Camp Wil-A-Way, Fort Yargo State Park, Winder, Georgia, and field trips to Grant Park Zoo and to the Stone Mountain Park Game Ranch.

Transportation was provided the first half of the school year by local taxi service and the last half by a combination of taxi service and a minibus purchased for the program. Transporation for the summer session was provided by two minibuses.

Georgia Academy for the Blind

A 36 week residential program of education and related experiences was provided to sixteen deaf-blind children at the Georgia Academy for the Blind. The program was funded through cooperative agreements with ESEA Title I and Title VI-C funds.

In-service training was provided to teachers, houseparents and other designated personnel with the objective of more effective operation and evaluation of activities.

Teachers and related personnel determined the level of functioning of each child in the areas of self-care skills, motor development and social awareness. Some of these children were involved in previous projects. For these children, baseline data was a natural outgrowth of ongoing evaluation processes. For children who were new to the program, determination of level functioning in the stipulated area was made from parent reports, consultant evaluation and staff observation of behavior.

School Year 1972-73

The establishment of an Early Childhood Center with an emphasis on preschool language development enabled the Georgia Center for the Multihandicapped Children day classes to move into a regular elementary school setting in September, 1972. Children are transported by two minibuses from all over metropolitan Atlanta. Individual language development and speech therapy are available for children who need specific training in these areas. Total communication is emphasized. One class is at a level of developmental readiness; the other may be characterized as pre-academic. Ten children are currently enrolled in the day classes.

The pace of the diagnostic and educational evaluation has increased so that at this writing (11-1-72) evaluation has been completed on ten children; six are in evaluation now, and twenty are awaiting evaluation.

The first two applications for evaluation from outside Georgia have been received. These two children are on the waiting list pending receipt of all their records.

Placement of Children Evaluated

Two children evaluated at the Georgia Center were placed in regular classes for the visually impaired. One is in a self-contained preschool class; the other in a regular first grade served by an itinerant teacher of the visually impaired.

Three children were placed in classes at the Georgia School for the Deaf in Cave Spring in pre-primary and primary classes.

Six children were enrolled at the Atlanta Area School for the Deaf. The Atlanta Area School is a state day school which now provides programs to pre-primary and primary deaf children in the six county metropolitan Atlanta areas. Part of its mission is to serve deaf children who function on the retarded level.

One child is in the Early Childhood Training Program at the Cerebral Palsy School; one in the Early Childhood Language Development Program in DeKalb County; one in the Behavior Modification Program at Georgia Mental Health Institute. Others have been placed in training centers.

The staff of the Georgia Center has been increased to accommodate the needs of the evaluation component and the day classes:

1 Director
1 Social Worker
1 Secretary
3 Teacher-evaluators
2 Teachers
4 Teacher Assistants
1 Child Care Aide

Georgia Academy for the Blind

The present program for sixteen deaf-blind children demonstrates that some of the participants will be functioning at a significantly more independent level. In addition there is evident a need for a residential program to serve deaf-blind children at a lower level of functioning. Future plans and budget requests will reflect the need for changes in staffing to meet these needs.

Goals and Objectives, School Year 1973-74

The goal of the Deaf-Blind Program is to provide appropriate and comprehensive programs in the state for all deaf-blind children, and to make available to the region the services that have been developed to serve deaf-blind children.

OBJECTIVE 1.

Continue to survey and identify deaf-blind children and suspected deaf-blind children. Maintain the registry of deaf-blind children.

Strategy

1. Visit homes of children referred.
2. Maintain registry of children eligible for evaluation.
3. Disseminate brochure through SDE Newsletter; Georgia Department of Physical Health News, Department of Family and Children Services Bulletin, physicians and psychologists offices.
4. Cooperate with the Department of Human Resources "Advocacy Program" to receive referrals and follow up on the children referred as potential candidates for service by the Georgia Center.

Evaluation

1. Record the number of requests for service, program presentations, etc.
2. Record the number of children referred.
3. Record the number of children eligible for evaluation and for the registry of deaf-blind children.

OBJECTIVE 2.

Continue providing evaluation and diagnostic service.

Strategy

1. Serve children eligible for the Georgia Center for Multihandicapped.
2. Provide medical examinations as indicated.
3. Assess psychological needs.
4. Evaluate educational potential for each child.

5. Recommend appropriate placement.
6. Provide for social, recreational and other needs of children.

Evaluation

1. Record the number of children admitted for multidisciplinary evaluation.
2. Record the number and type of placement.
3. Provide follow-up services to determine appropriateness of placement.

OBJECTIVE 3.

Continue the day program for twelve deaf-blind children from the metropolitan Atlanta area.

Strategy

1. Define behavioral and instructional objectives for each child.
2. Prescribe teaching skills to meet individual needs.
3. Evaluate child's progress each month.
4. Videotape interaction of teachers and children; children and environment.

Evaluation

1. Videotape regularly to assess child's progress and evaluate teaching strategies.
2. Invite outside experts to analyze tapes in terms of objectives defined and goals achieved.
3. Chart progress of child in self-help, activities of daily living, language development, visual and auditory training.

OBJECTIVE 4.

Continue to seek placement of deaf-blind children in public and private educational programs.

Strategy

1. Consult with local school systems, community day care and training centers to place children in ongoing educational programs.
2. Schedule presentations to personnel of state, local and community agencies to encourage and help implement local services.

Evaluation

1. Record the number of children referred to programs who are admitted and retained in programs.
2. Record number of new programs and services offered throughout the state.

OBJECTIVE 5.

Broaden the program of providing parent and child-home training in the area of deaf-blind.

Rationale

Recent referrals to the Georgia Program reveal the needs of very young multisensory impaired children and their parents for counseling, parent-child workshops and direct agency services within their home communities until their children are able to enter the diagnostic and evaluation program at Aidmore, for assessment of their educational potential and subsequent placement. There is further need for follow-up education and training services to parents whose children have been evaluated and who are awaiting placement. Placement may depend on an opening in an existing program, or upon a child's developing certain self-care abilities, or reaching a certain age. It may depend on community development of the right program to meet his needs. Follow-up services are essential to circumvent and reduce all these delays in placement. The work of the social worker at the Georgia Center for the Multihandicapped has provided much supportive help to parents, and much stimulation to community agencies, but it has also uncovered the depth of need for regular parent-child workshops and other services within the ten congressional districts of the state and throughout the region. To meet these needs we are requesting the position of parent-educator and community services worker to be placed on the staff of the Georgia Academy for the Blind.

Strategy

1. Employ full-time parent-educator/community service worker to work in the field, to be placed on the staff of the Georgia Academy for the Blind to meet objectives four and five.
2. Develop a parent education manual and other materials for helping parents work with children.
3. Workshops for parents and children.
4. Provide parents with a list of helping agencies in immediate vicinity.

Evaluation

1. Record the number of parents and children worked with, the number of home visits made.
2. Submit questionnaire or evaluation form to parents to evaluate effectiveness of manual.
3. Chart improvement of children in areas of training by progress chart regularly marked.
4. Record number of calls from parents for additional services.

OBJECTIVE 6.

Expand the Georgia Academy for the Blind, Deaf-Blind Unit program from sixteen to twenty deaf-blind children, and improve quality of program.

Rationale

It has further become apparent, through the referral and evaluation services, that there is a great need for a residential program to serve the more severely involved deaf-blind children of the state and region. To provide these services, more personnel are needed in education, child care, nursing and therapy to meet the multifaceted needs of children who are at a low developmental level. Increased facilities are needed as well, so housing units will be added by the state to take care of additional multisensory impaired children. The number of deaf-blind children will be increased from sixteen to twenty.

Strategy

1. Add staff: Language Development Teacher, Occupational Therapist, two Teacher Aides, two Houseparents, part-time Nurse, a Driver-Custodian.
2. Add housing units.
3. Expand nursing services.
4. Provide physiotherapy and occupational therapy.
5. Purchase auditory training equipment.
6. Purchase educational materials and supplies for older children.

Evaluation

1. Keep detailed records on progress of children in language development, activities of daily living, visual and auditory development.
2. Maintain anecdotal records, monthly summaries.

OBJECTIVE 7.

Design and develop sequential and individualized curriculum for preschool and school age deaf-blind children.

Rationale

Preliminary efforts of the educational staff at the Georgia Center, in the day classes, and in the residential program, to develop curriculum materials have provided baseline data and materials to each program. There is need now to develop a sequential curriculum which will be a structural guide to parents and houseparents, home teachers, therapists and teachers in the total training program necessary for young deaf-blind children. The Georgia program would like to employ a teacher-consultant to coordinate this activity as a prime responsibility during the summer of 1973. No additional position or funds are requested for this objective.

Strategy

1. Assemble other curriculum guides and study them.
2. Employ curriculum consultant to work with teachers in writing up curriculum.
3. Outline areas that would be covered in sequential curriculum guide.
4. Prepare first draft of curriculum with subsequent revision until revision is completed.
5. Publish multiple copies of revised sequential curriculum for dissemination of field testing.

Evaluation

1. Field test and record recommendations of personnel using curriculum guide.
2. Revise according to recommendations and needs of field.

OBJECTIVE 8.

Extend the diagnostic and evaluative services to deaf-blind children residing outside the state of Georgia.

Rationale

Requests from other states for educational evaluation of deaf-blind children make it desirable to extend the services of the Georgia Center to deaf-blind children from the region who need a long-term evaluation. To be successful, it will be necessary to have pre-evaluation and follow-up services which are usually done by the social worker of the Georgia Center completed by the state which has referred the child.

Strategy

1. Invite other states to take advantage of services offered.
2. Accept applications from other states within the Southeastern Region.
3. Admit children who are or are suspected of being deaf-blind to Georgia Center for the Multihandicapped.
4. Provide medical examinations as indicated.
5. Assess psychological needs.
6. Evaluate educational potential of each child.
7. Recommend appropriate placement to coordinator of deaf-blind services in child's state.
8. Provide observation and training opportunities to educators and community agents in referring states.

Evaluation

1. Record number of referrals received from other states.
2. Record number of children served.
3. Evaluate success of service in terms of placement, services initiated at local level.

OBJECTIVE 9.

Encourage centralization of residential programs for deaf-blind children confined to institutions.

Rationale

There are a number of deaf-blind persons who are residents of state institutions for the retarded, where they receive only minimal stimulation specific to their needs. The centralization of services to the deaf-blind within the state hospitals is essential to improve the quality of life for these persons. Education and training programs set up in one or two state hospitals, so that all deaf-blind persons in the state who require custodial residential care could be placed in hospitals where programs for the deaf-blind are available, would achieve this goal.

Strategy

1. Work with the Department of Human Resources to centralize services to deaf-blind persons residing in institutions.
2. Meet with staff representatives of state institutions and admissions offices to stimulate action toward this end.
3. Provide observation opportunities and consultative help to institutions where deaf-blind students are patients.

Evaluation

Report actions taken by the Department of Human Resources to provide coordinated and centralized services such as designation of state facilities to handle such children and the number of new programs within institutions.

OBJECTIVE 10

Provide in-service education to Georgia Program staff, educational, consultative and child care personnel.

Rationale

Changes in staff, in objectives, and the receipt of new information and materials directed to the education and training of the deaf-blind require ongoing in-service education of personnel.

Strategy

In-service education schedule prepared.

Evaluation

1. Record improved services to children.
2. Evaluate competencies and increased teaching techniques of staff.
3. Recommend additional training programs.

We Look to the Future

The Georgia Program for the Deaf-Blind is a comprehensive program which has served the state's multihandicapped children since 1969. Each year the services have been expanded. It has been demonstrated that almost any service which is needed to serve deaf-blind children can be provided through the various components of the Georgia Program for the Deaf-Blind.

Current Status

GEORGIA CENTER FOR THE MULTIHANDICAPPED

Evaluation Center

The evaluation center located at Elks Aidmore Hospital in Atlanta, Georgia provides comprehensive evaluation for deaf-blind children within the state and region. The diagnostic evaluation includes psychological, educational placement, parent counseling and training.

Children being evaluated are residents of Elks Aidmore Hospital from Monday to Friday, for approximately two or three weeks. Parents receive training on Fridays when they come to pick up their children for the weekends. Each child evaluated is followed by social work services until placement is accomplished. Each educational placement is re-evaluated annually, and children are re-evaluated before subsequent placement is made. One hundred and forty-five children have been evaluated since 1969 (including five re-evaluations); 124 placed; ninety-seven on the deaf-blind registry; 175 receiving social work services.

Day Classes

The educational component of the Georgia Center for the Multihandicapped provides two classroom units for multisensory impaired children from the metropolitan Atlanta area. Transportation is provided from five different counties to the Doraville Center for Early Childhood, a DeKalb County School. Twelve children live at home and attend school on a day basis. Development of academic and social skills is the prime objective of this program, with the goal of placing children in traditional education programs in their local communities as soon as their communication skills have developed to such an extent that they can fit into classes. Seven children have been placed after training in day classes. Twelve are currently enrolled.

Curriculum Guide to Services

An extended guide to services to deaf-blind children was developed by the staff of the Georgia Center during the summer and fall of 1973. It will be field tested and revised prior to publication in fiscal year 1974.

GEORGIA ACADEMY FOR THE BLIND

Residential Education Program

Deaf-blind children from throughout Georgia who need and can profit from a residential education program are accepted into the Georgia Academy for the Blind, Shurling Campus, where twenty multihandicapped children are served twenty-four hours a day. The prime objective of this component is to develop in a residential setting academic, social and community living skills commensurate with the child's ability. A full-time director now coordinates and administers the multihandicapped program which includes the Deaf Blind Unit.

Parent Education

The employment of a parent-community educator to serve the state is expected to increase significantly parental involvement in child progress.

Other Services

Current funding allows for contracted services of both a physical therapist and an occupational therapist as pupil needs dictate.

TUTOR-COMPANION PROGRAM

A tutor-companion is being provided to a deaf-blind child who is enrolled in a class for preschool deaf children in Dougherty County, Georgia, through a contractual arrangement with the Southeast Regional Center for Deaf-Blind Children. In-service training will be required for the person employed as tutor-companion through the various services of the Georgia Program for the Deaf-Blind.

Goals and Objectives, School Year 1974-75

OBJECTIVE 1

Continue to survey and identify deaf-blind and suspected deaf-blind children. Maintain the registry of deaf-blind children.

Strategy

1. Visit homes of children referred.
2. Maintain registry of children eligible for evaluation.
3. Disseminate brochure through SDE Newsletter, Georgia Department of Physical Health News, Department of Family and Children Services Bulletin, physicians' and psychologists' offices.
4. Cooperate with the Department of Human Resources "Advocacy Program" to receive referrals and follow up on the children referred as potential candidates for service by the Georgia Center.

Evaluation

1. Record the number of requests for service, program presentations, etc.
2. Record the number of children referred.
3. Record the number of children eligible for evaluation and for the registry of deaf-blind children.

OBJECTIVE 2.

Continue providing evaluation and diagnostic services.

Strategy

1. Serve children eligible for the Georgia Center for Multihandicapped.
2. Provide medical examinations as indicated.
3. Assess psychological needs.
4. Evaluate educational potential for each child.
5. Recommend appropriate placement.
6. Provide for social, recreational and other needs of children.

Evaluation

1. Record the number of children admitted for multidisciplinary evaluation.
2. Record the number and type of placement.
3. Provide follow-up services to determine appropriateness of placement.

OBJECTIVE 3.

Continue the day program for twelve deaf-blind children from the metropolitan Atlanta area.

Strategy

1. Define behavioral and instructional objectives for each child.
2. Prescribe teaching skills to meet individual needs.
3. Evaluate child's progress each month.
4. Videotape interaction of teachers and children; children and environment.

Evaluation

1. Videotape regularly to assess child's progress and evaluate teaching strategies.
2. Invite outside expert to analyze tapes in terms of objectives defined and goals achieved.
3. Chart progress of child in self-help, activities of daily living, language development, visual and auditory training.

OBJECTIVE 4.

Continue to seek placement of deaf-blind children in public and private educational programs.

Strategy

1. Consult with local school systems, community day care and training centers to place children in ongoing educational programs.
2. Schedule presentations to personnel of state, local and community agencies to encourage and help implement local services.

Evaluation

1. Record the number of children referred to programs who are admitted and retained in programs.
2. Record number of new programs and services offered throughout the state.

OBJECTIVE 5.

Provide diagnosis and evaluation services and classes to deaf-blind children from twelve to sixteen years of age.

Rationale

Requests have been increased for services to older deaf-blind students who are not presently placed in educational programs.

Strategy

1. Publicize availability of services through brochures, newsletters, conferences and workshops.
2. Add one teacher position to the Georgia Center for the Multihandicapped to initiate day classes to serve

older deaf-blind children in the metropolitan Atlanta area.

3. Arrange evaluation schedule so that several older students may be received for evaluation at one time.

Evaluation

Evaluate success in terms of number of referrals received, placements effected for older students, available programs instituted throughout the state.

OBJECTIVE 6.

Expand the Georgia Academy for the Blind, Deaf-Blind Unit to from twenty to twenty-four children and further improve the quality of the program.

Rationale

Training and learning for the multisensory impaired child is a slow and tedious process, and more personnel are required to meet the needs of children of low developmental level. Projected plans call for an increase in the number of deaf-blind children and for inclusion in the program of children who are more severely impaired. It is further hoped and expected that younger children can be brought into the program since the earlier formalized instruction can be implemented for a given child, the greater the probability for positive results. Staffing patterns must reflect increased number of children served and increased quality of services.

Strategy

1. Increase staff.
2. Improve housing units.
3. Expand nursing and medical services.
4. Provide more extensive physical and occupational therapy.
5. Provide a social worker to promote continuing parent involvement.
6. Provide educational materials and supplies needed for program success.
7. Make available to staff relevant consultant direction and in-service training.
8. Increase effort to inform the general public of program objectives.

Evaluation

1. Maintain comprehensive records of children's progress in language development, activities of daily living, visual and auditory development.
2. Maintain anecdotal records of student behaviors and monthly summaries of observed improvement.

OBJECTIVE 7.

Work with other agencies to develop educational and pre-vocational programs for older deaf-blind children.

Strategy

Institute meetings with Georgia Department of Human Resources, Vocational Rehabilitation, and Georgia Industries and Sheltered Workshops to develop complex of services for pre-vocational and vocational deaf-blind students.

Evaluation

Evaluation will be in terms of number of services developed to serve pre-vocational and vocational deaf-blind students and placement of students in sheltered workshops or in employment.

OBJECTIVE 8.

Provide tutor-companion to individual deaf-blind students enrolled in educational programs in local communities.

Strategy

1. Arrangements will be made through the Georgia Program for the Deaf-Blind for tutor-companions for local education agencies.
2. Contractual arrangements will be made from Southeast Regional Center for Deaf-Blind through the Georgia Department of Education to local education agencies.
3. In-service education will be required of each person employed as tutor-companion through the Georgia Center for the Multihandicapped or the Georgia Academy for the Blind.

Evaluation

Careful records will be kept of each child's progress. Evaluation of success will be made from the child's progress through these records.

Some Observations on Services for the Deaf-Blind

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Scarcely ten years ago, any employment of deaf-blind people was considered to be remarkable; and, with the exception of a handful of highly superior individuals, the employment of the deaf-blind under fully competitive conditions was almost unheard of.

Early Services for the Deaf-Blind

The Industrial Home for the Blind has employed deaf-blind people in its sheltered workshops without interruption since 1918. In 1945, it inaugurated a program of specialized services for its deaf-blind clientele. This program began with the employment of a specialist in services for the deaf-blind and later added two more such specialists. The responsibilities of these workers fell into two broad categories:

1. providing for the deaf-blind clients those specialized services required to meet the special needs growing out of their deafness and blindness and
2. training the staff of the agency in methods of communicating with deaf-blind individuals and providing consultation on ways in which services designed for hearing blind persons might be adapted, where necessary, to serve the deaf-blind.

Through this program of specialized services for the deaf-blind, the agency's full program of services for hearing blind persons, with certain obvious exceptions – such as training in the playing of musical instruments, training in fine auditory localization, etc. – was offered to its deaf-blind clientele. As many as twenty-eight deaf-blind clients at a time were provided with employment in the agency's sheltered workshops. In conjunction with its social workers, rehabilitation counselors, rehabilitation teachers, and recreation workers, the specialists in services for the deaf-blind developed an active register of over one hundred deaf-blind individuals, providing, as needed, social adjustment services, rehabilitation counseling, training in skills of daily living, communication, and opportunities to participate in recreational activities of interest to them.

In 1959, the Industrial Home for the Blind published a seven volume report on a study of the "Rehabilitation of Deaf-Blind Persons" which it had conducted from 1956 to 1958 with the support of the then Office of Vocational Rehabilitation of the U.S. Department of Health, Education, and Welfare. The report engendered a great deal of interest in services for deaf-blind adults; but this interest failed to result in any significant increase in services for the deaf-blind.

From time to time over the years, agencies for the blind provided employment for some deaf-blind persons in their sheltered workshops and training for others in their homes. However, these efforts, generally, were motivated by a desire to meet the needs of particular deaf-blind individuals and failed to reach out to find and serve other deaf-blind people in their communities. Consequently, when those who were served moved away, or, for other reasons, withdrew from service, the efforts involved in serving them lapsed and the experience and knowledge gained through these efforts failed to benefit other deaf-blind individuals.

It may be noted that, until recent years, deaf-blind children, with very few exceptions, were educated in residential schools for the blind. This probably resulted from the fact that the communication and mobility problems of the deaf-blind are more similar to those of the hearing blind than to those of the seeing deaf. This fact, too, together with the fact that work for the adult blind has a history of providing sheltered employment which extends over more than one hundred years, probably explains why the limited services that were provided for deaf-blind adults over the years were also based in the field of work for the blind.

National Center for Deaf-Blind Youths and Adults

In order to take advantage of the high interest in services for deaf-blind adults engendered by the report published in 1959, the Industrial Home for the Blind, with support of the Social and Rehabilitation Service of the Department of Health, Education and Welfare, embarked on a regional research and demonstration project in 1962 which continued until it was succeeded, in 1969, by the National Center for Deaf-Blind Youths and Adults. The project was designed to demonstrate the feasibility of rehabilitation services for the deaf-blind and to stimulate the development of such services for this group in state and local rehabilitation agencies. Within a few years, a number of breakthroughs were achieved and, before the project terminated, several agencies were committed to provide sheltered employment and other services for the deaf-blind and a number of deaf-blind individuals had been placed in fully competitive employment.

Of sixty-two deaf-blind youths and adults who received evaluation and rehabilitation training at the temporary headquarters of the National Center prior to January 1, 1974, eighteen percent are working in fully competitive employment; thirty-one percent are in sheltered workshops; eight percent are homemakers; five percent are employed in home industry or family business enterprises; eight percent are enrolled in programs of higher education; three percent are continuing training at other facilities; and five percent, who completed their training late in the year, are awaiting placement. The remainder of the group included three who returned to custodial institutions; two who are ill; one who was reclassified as "not deaf", six who are receiving services in their homes, including two whose families would not permit them to accept employment; and two who died. In addition, through the joint efforts of National Center personnel and personnel of cooperating agencies, employment was obtained for sixteen other deaf-blind persons (four in competitive employment, eleven in sheltered workshops, and one in a home industry program), and we have information on still other deaf-blind persons who are employed.

Effects of Early Success in Rehabilitation

These figures reflect an encouraging beginning; but we see evidence of a fairly widespread misconception that the fact that success in the rehabilitation of deaf-blind persons is possible signifies that it can be achieved easily, without the need of special understanding and special effort. There is some danger that many well-intentioned efforts to serve deaf-blind people will prove to be abortive because of a failure to lay a solid foundation of experience and training for those who undertake them. Also, because of the widespread tendency to measure accomplishment almost exclusively in quantitative terms, we see a danger of concentrating primary attention on meeting the needs of the most capable and least handicapped deaf-blind individuals in order to present a picture of inexpensive and spectacular success.

A good part of the success in the rehabilitation of deaf-blind persons achieved during the past few years can be attributed to the groundwork that had been laid by the regional research and demonstration project which immediately preceded the National Center for Deaf-Blind Youths and Adults. While that project was designed to operate primarly within Regions I, II, and III of the Department of Health, Education, and Welfare, its services were extended into a number of other states on the request of agencies within those states, and it produced a nucleus of experienced personnel as well as a fairly large number of personnel throughout the United States with a limited but significant amount of experience in working directly with deaf-blind individuals. The enthusiasm and the convictions which these personnel developed as a result of satisfying experiences in serving deaf-blind persons had positive spillover effects on agency and community attitudes toward rehabilitation services for the deaf-blind in many parts of the country. However, while this and related developments certainly contributed to some of the current success in serving the deaf-blind, they cannot be expected to form an adequate foundation for the substantial expansion and improvement in services for the deaf-blind that will be required in the years ahead if deaf-blind people in the United States and its jurisdictions are to be afforded adequate opportunities for rehabilitation and self-fulfillment. Further, we must recognize that we have been passing through a long period of expanding labor markets and interest in the welfare of severely handicapped people. With contracted employment opportunities and related consequences of the energy shortage and the increasing competition for government and voluntary funds to help meet the newly appreciated needs of large numbers of disadvantaged people, work for the deaf-blind will need to demonstrate its ability to realize solid accomplishments if it is to deserve and receive the support it will require in the years ahead.

A Definition of "Deaf-Blind"

A prerequisite for a successful attack on any problem is a clear definition of the problem itself. A first, fundamental step in meeting this prerequisite for attacking the problem of inadequate services for the deaf-blind must be the development of a clear and objective definition of "deaf-blind." Sound planning to meet the needs of the deaf-blind requires the development of valid data on the composition and distribution of this group of handicapped people. This cannot be accomplished until we can decide on a criteria for determining who is "deaf-blind." If we are to avoid dissipating much of the money and effort intended to benefit the deaf-blind by serving people with marginal auditory and visual deficits or by serving those – such as the mentally retarded – who are sometimes mistaken for deaf-blind people, we must agree on a definition of "deaf-blind" that will help us to identify the individuals who have a proper claim to services offered under programs designed for this most severely handicapped group.

Recognizing that the effect of the combination of a significant deficit in hearing and in vision may be greater than the sum of the effects of each of these deficits, we believe that a two-tier definition of "deaf-blind" is indicated:

1. a liberal but clear definition that might be used as the condition of eligibility for isolated specialized services for the deaf-blind or eligibility for full-time enrollment in a rehabilitation program for the deaf, the blind, or the severely multihandicapped with specialists available under the program to help meet the specific problems growing out of the combination of

significant auditory and visual deficits; and

2. a restrictive definition to assure that invididuals with very substantial auditory and visual deficits will be given highest priority for full service under specialized programs designed to serve the deaf-blind.

The National Center maintains such a two-tier definition, offering the full resources of its residential evaluation and rehabilitation training program to those who fall within the restrictive definition of "deaf-blind" and making available a variety of specialized services directly or through cooperating state and local agencies to those who fall within the liberal definition of "deaf-blind." Our two-tier definition, we might mention, is adequately functional at present, but we hope to refine it as new knowledge and expertise become available for this purpose.

Minimizing the Handicap

It is a cardinal principle of rehabilitation that training around any handicap should not proceed until every reasonable possibility for reducing or eliminating the handicap has been exhausted. Unquestionably, the first possibility that should be explored is that which may be offered through medical or surgical treatment; but, when the handicap itself cannot be reduced or eliminated, the limiting effects of the handicap can often be reduced through the proper use of sensory aids. Lenses, hearing aids, and other ocular and auditory devices can often be used to maximize the usefulness of residual vision or residual hearing. However, another means of minimizing the handicapping effects of deafness and blindness is the employment of mechanical and electronic aids to enhance the usefulness of the remaining senses.

Sensory Aids

Various devices employed in the reading and writing of braille are now conventional. The Opticon, an electronic device that makes it possible to read ordinary print by touch, has already proved to be of value and holds much promise for some deaf-blind individuals in computer programming, in studying, etc. A number of electronic devices for the wireless transmission of vibratory signals have proved useful to alert deaf-blind persons to the ringing of a doorbell, the sounding of a fire alarm, etc., and we now see good promise of greatly improving the versatility and reliability of this method of communication in the near future. The transmission of braille by telephone has been amply demonstrated and holds exciting promise for increasing the ability of deaf-blind people to communicate with each other over considerable distances and, through the use of available typewriter keyboard and visual printout add-on devices, to communicate with people who can see and who have not had occasion to learn braille. We may hope that, in the not too distant future, the transmission, by radio, of braille and/or embossed print will make it possible for deaf-blind individuals to communicate with almost anyone in their immediate vicinity without the necessity of maintaining physical contact with such a person or depending on a telephone line connection with him. Such an accomplishment will offer not only practical benefits to the deaf-blind individual but will provide him with a kind of emancipation from the need to accommodate himself to the location and movements of others in the course of communicating with them that may hold important psychological benefits for him.

Research in the development and evaluation of sensory aids has, too often, been dismissed as mere gadgeteering. In the past, many starts on the development of sensory aids have been made by volunteers and even by professional engineers who have not had the funds or the opportunity to carry their work in this area beyond the excitement of its novelty. We are now in a fairly good position to conduct well-planned, long-range research in the development of sensory aids for the deaf-blind. This kind of research has already paid good dividends and there is a need to conduct much more of it on a coordinated basis to avoid duplication of effort and to pool the results of all competent effort in this area with the objective of giving the deaf-blind their fair share of what modern day technology has to contribute toward the minimizing of their handicap.

Perception and Conceptualization

There is a great deal of research that needs to be done into the means of perception and the methods of conceptualization of deaf-blind individuals. We need to study the more subtle aspects of body language so that the deaf-blind persons might be taught how to enhance their ability to sense the attitudes, the moods, and the reactions of the people with whom they communicate through the clasp of the hand, the rhythm of the walk, the presence or absence of tenseness, etc. Even many of us who have a great deal of contact with deaf-blind people and who think we have a fairly sophisticated understanding of them are often astounded at the thoroughness and accuracy of the assessments that some of them can make of other people through seemingly casual contact. We need to learn more about how this is accomplished.

We need to study how to preserve, strengthen, and enhance imagery acquired before the loss of vision or the loss of hearing. In this connection, we need to study the extent to which information acquired through one sense can be converted into the language or medium of another sense. People who lose their sight report that they visualize environments in which they formerly lived with sight as they saw them but that, when they return to such environments, they can largely update the picture of the environments which they have preserved in their mind's eye with information they acquire through touch, sound, the kinesthetic sense, and even the olfactory sense. Some people who have, or who have had, a small amount of vision report that they are visually minded and that they can enhance their visual images with information they acquire through their remaining senses but which they could never perceive visually. Totally deaf people who lost their hearing in childhood demonstrate their ability to reproduce melody and other sounds that they may not have experienced for many years. Some of them show an uncanny sense of the appropriateness of the sound – aside from the meaning – of a word or a phrase in a sentence.

We speak a good deal about blind people learning through the sense of touch, despite the fact that the sense of touch provides little or no information beyond that related to temperature, texture, and the shape of very small objects. Relationships, proportion, size, etc., except where very small dimensions are involved, are perceived through the kinesthetic sense functioning in conjunction with the tactual sense. The fingers, the hands, the arms, and the feet and legs are employed in the use of the kinesthetic sense (depending upon the size of the object or the area that is being examined). We know of no text or manual on the techniques of perceiving through kinesthesis and touch. There is a need to study the operation of these senses and to develop and record techniques for teaching how to make best use of them.

The foregoing are only randomly selected examples of areas that require careful study to improve our ability to teach deaf-blind children and adults how to broaden and better particularize their knowledge and increase their skills. We do not believe that very much real understanding in these areas can be achieved through conventional techniques of research. We must depend very largely on the introspection and insight of perceptive, sensitive deaf-blind individuals for gathering information in these areas. Research in these areas, we believe, requires investigators who are highly competent in the use of sound research techniques, who have had extensive experience in work with the deaf-blind, and who can maintain a close and sensitive relationship, based upon genuine mutual respect, with the deaf-blind individuals involved in their research. The investigator and the subjects of his study in such research, we believe, should undergo a period of joint training to minimize semantic differences in their thinking and to achieve a high degree of common purpose for the research which they will jointly conduct. Through careful interviews, strengthened by thoughtful prodding and questioning, the investigator should elicit from the deaf-blind subjects as much information as possible about how they think, the content and structure of their imagery, and the capacities and limitations that determine it. From such information, the investigator may form impressions and postulate hypotheses, which should be subject to critical examination by the subjects, that might be tested for reliability and validity through conventional research techniques. Only through such an approach, we believe, can meaningful information be developed that could be useful in the education and rehabilitation of deaf-blind people.

Staff Development

Unfortunately, the limited experience in the field of services for the deaf-blind and the meagerness of the literature that exists in this field provide little opportunity for accelerating the preparation of the staff that is required to meet the challenge that confronts us, a challenge of overcoming a substantial delinquency in the development of adequate skill and knowledge to meet the educational and rehabilitative needs of most deaf-blind persons. Far too little essential knowledge can be acquired through studying the literature and there are far too few individuals who have experience to impart that can provide an adequate appreciation of the special needs and potentialities of deaf-blind people and of the skill and knowledge that can help to meet these needs and realize these potentialities and further, who are in a position to point out the vast area of misinformation and lack of information in the field of services to the deaf-blind. There is no way to effectively bypass any substantial part of the time-consuming necessity for learning by doing. To work with the deaf-blind effectively, it is essential to acquire experience to provide a framework in which to adapt the skills and knowledge that comprise the various helping professions that can contribute to this work. Teachers in the field of services to the deaf-blind and consultants in this field cannot be created by the mere acquisition of appropriate payroll titles. Experience is an indispensable ingredient in the qualification to teach new and prospective workers in the field of services to the deaf-blind and to provide meaningful consultation in this field. We strongly believe that, during the next ten or fifteen years at least, teachers of new and prospective workers in the field of services for the deaf-blind should be limited to individuals who, despite any other qualifications they may have to offer, devote some of their time to performing the skills they teach and consultants should be individuals who are closely involved in the activities and the kind of planning in which they offer consultation.

Training in Services

The National Center offers a one week program of Training in Services to Deaf-Blind Youths and Adults to workers in agencies for the blind and agencies for the deaf and to others who are likely to work with deaf-blind persons. This program includes four and a half days and three evenings of training, consisting of lectures, seminars, observation, and practicum.

A large amount of individual attention is required by those who enroll in this program to enable them to relate the skills and knowledge they acquire under the program to the responsibilities of their respective professional positions. Because of this, we find it desirable to limit enrollment in each section of the program to six. Also, because the staff who instruct in this program are the same staff who provide rehabilitation services for deaf-blind trainees at the National Center and who, from time to time, are called upon to provide consultation and demonstration services for other agencies interested in serving the deaf-blind, the program cannot be repeated more than four or five times a year without running the risk of attenuating the rehabilitation services offered by the National Center. Despite this, seventy-nine staff members, drawn from thirty-six states and the District of Columbia, completed the program prior to the first of this year and at least thirty more are expected to complete the program before the end of the year. Most of those who have completed the program devote significant portions of their time to serving deaf-blind clients of their employing agencies and cooperate very closely with the staff of the National Center. The quality of this cooperation may best be seen in the fact that the center's regional representatives frequently characterize many of the workers who have completed the program as adjunct staff of the center.

Counterpart training is offered to individual workers employed by agencies cooperating with the National Center when it is clear that this training will result in the early introduction or expansion of a specialized service for deaf-blind persons. In this training, which is generally planned for a two week period, the worker invests several days in observing the rehabilitation and research programs of the National Center and in becoming familiar with the objectives and philosophy that underlie these programs. During the balance of the training period, the worker trains with his counterpart at the National Center — if he is a rehabilitation counselor, he will train with the center's rehabilitation counselor, if he is a mobility instructor, he will train with the center's mobility instructor, etc. This affords him an opportunity to observe and practice the special approaches and techniques employed in adapting and supplementing the skills and knowledge of his professional discipline to serve deaf-blind persons.

Field training has been offered to graduate and undergraduate students in social work, speech therapy, and audiology. To the extent that the demands on its staff and resources will permit, the center is prepared to offer field training in these and in any other area in which it is qualified to do so, provided the training is requested by the students involved and provided these students show some promise of using this training to benefit deaf-blind persons. The National Center is not equipped to serve as a regular field placement resource for colleges and universities but it is eager to do what it can to strengthen the interest in service to the deaf-blind of college and university students who may be potential workers in this field of service or who may enter allied fields of service where they may be able to contribute to the expansion of services for deaf-blind people and the acceptance of deaf-blind individuals in the professional and/or lay communities.

After the National Center moves into its specially designed permanent facilities which are now under construction, it hopes to expand and diversify its staff development and training services. It will continue to offer short-term training for new and prospective workers in the field of services to the deaf-blind who have completed their professional or paraprofessional training or whose work may not require such training. In addition, it plans to affiliate with one or more universities and to provide long-term training in conjunction with graduate and undergraduate programs of study in the various professional disciplines that fill important roles in serving deaf-blind persons. This training will be offered to individuals interested in careers in service to deaf-blind persons and, in some cases, may provide fellowships and residencies.

One of the best promises for substantially expanding resources for the rehabilitation of deaf-blind youths and adults, we believe, may lie in the training of specialists in service to the deaf-blind for work in rehabilitation agencies for the blind, the deaf, or the severely multihandicapped. Many individuals who are deaf-blind within a liberal definition of this term under the kind of two-tier definition referred to earlier in this paper and some, perhaps, with more serious auditory and visual deficits than this group could probably be well served in rehabilitation agencies which do not specialize in services for the deaf-blind but which are interested in serving them. Such agencies, prepared to supplement their regular personnel with specialists equipped to help meet the unique problems that grow out of the combination of deafness and blindness — those in the area of communication, for example — and to help the regular personnel to adapt the use of their skills and knowledge to serve their deaf-blind clientele, could make it possible to serve many deaf-blind individuals in or close to their home communities and to avoid an unnecessary drain on the facilities and services of the National Center which are designed for those deaf-blind individuals who require comprehensive, in-depth specialized evaluation and rehabilitation training. We anticipate that, in time, such agencies — with the help of the National Center's regional representatives and other consultants, where required — will serve many times as many deaf-blind youths and adults as will be served at the headquarters of the National Center.

Role of the National Center

We expect that the clients served at our headquarters will, generally, be deaf-blind individuals with rehabilitation needs that will require a full staff of specialists in services for the deaf-blind and the kind of specially designed facilities that will be available only at our headquarters. In this way, the National Center will serve as a court of last resort for those deaf-blind clients who could not be served at other agencies and, at the same time, will provide an opportunity for developing and testing rehabilitation methods for serving severely handicapped deaf-blind persons which could be used to enhance the capacities of agencies cooperating with the National Center to serve many of their deaf-blind clients. The National Center, too, will serve as a clearinghouse for problems and achievements in service to deaf-blind persons of agencies cooperating with it so that the experience of all of these agencies might be pooled with that of the National Center to provide a source of ideas and information that should be helpful in furthering both their collective and individual efforts on behalf of deaf-blind persons. The research resources of the National Center will be dedicated to meeting those needs for special skills, devices, and information which emerge from the total efforts of all cooperating agencies interested in the rehabilitation of deaf-blind individuals and its research department will make maximum use of the experience and thinking of these agencies in its research efforts.

The worth of whatever provisions all of us make for the education and rehabilitation of deaf-blind children, youths, and adults will ultimately be determined first, by the effect that these provisions have on the quality of life of the deaf-blind individuals served by them and, second, by the number of individuals we serve effectively and the severity of their auditory and visual deficits. While remunerative employment is a very important objective for many deaf-blind persons, it must not be allowed to become the sole criterion for determining their success or failure. Because this objective is so difficult to achieve with a major deficit in the two most important senses, we sometimes tend to lose sight of the fact that quite a number of deaf-blind persons — like many nonhandicapped people in the population at large — have no need for or any interest in remunerative employment. Many of these desire nothing more than to be able to effectively fill their role as homemakers. Others aspire to an active participation in their families' enterprises. Still others yearn to further their education, increase their self-reliance, or achieve any one of a number of objectives — sometimes, seemingly trivial objectives — to enhance their sense of their own worth and their ability to receive the respect of those whose esteem is important to them. Even a deaf-blind individual who, as a result of prolonged and severe deprivation or of severely limited personal endowments, has lived a life of nearly total dependence who can be helped to significantly reduce his dependence can be considered as rehabilitated if his achievement represents an optimum use of his residual capacities and provides him with a sense of personal accomplishment and satisfaction.

Because education and rehabilitation are provided under separate auspices and in separate settings, we tend to forget that they are – or, that, at least, they should be – integral parts of an extended effort to help the individual achieve self-fulfillment and a contributing role in his community. Since among the deaf-blind – as among any group of individuals – potentialities and aspirations are varied, there is need to provide as much diversity as possible in the rehabilitation programs we offer. We should be careful not to allow our concern for one segment of the deaf-blind population to cause us to become so preoccupied with its needs as to overlook the important needs of the entire deaf-blind population.

Our concern for the needs of those children whose deafness and blindness and, often, additional handicaps are the result of rubella can easily distort our perspective of the challenge of providing appropriate services for all of the deaf-blind. Without in any way minimizing our responsibility to help to meet the needs of the rubella children with whom we are now concerned, we should not lose sight of the fact that there are some children who are deaf-blind as a result of causes other than rubella and that some of these have potentialities that will not be adequately developed through programs designed for low-functioning deaf-blind children. Also, we should bear in mind that for every deaf-blind child in this country, there are probably about nine deaf-blind adults, most of whom have been very seriously neglected. Many of these deserve the very earliest and very best assistance we can offer to help them achieve some satisfaction out of life.

With the high incidence of deaf-blindness caused by rubella, it may be difficult to realize that deaf-blind children probably comprise no more than about ten percent of the total deaf-blind population. When retrolental fibroplasia was responsible for eighty to ninety percent of blind children of preschool age in the early 1950's, many felt that blind children constituted a large part of the total blind population. Yet, as late as 1966, twelve years after the cause of retrolental fibroplasia was identified and the condition became largely controlled, it was found that blind children under the age of twenty comprised *almost* ten percent of the blind population.(1) In *Facts About Blindness* (published by the American Foundation for the Blind) we note that "about ten percent of the world's population is of school age." In view of these facts, even though we have no reliable figures to indicate the portion of the deaf population that is of school age, we can assume that deaf-blind children of school age comprise no more than about ten percent of the deaf-blind population.

Some people seem to feel that efforts and resources expended in serving deaf-blind adults reduce our capacity to prepare to meet the needs of deaf-blind children when they become adults; but we can feel reassured in the knowledge that in meeting our obligation to deaf-blind adults, we are incidentally, but significantly, serving deaf-blind children: skills, devices, and information that prove effective to serve today's deaf-blind adults will be available to serve today's deaf-blind children when they become adults; and experience in serving adults helps to make clear the challenges and the opportunities that await today's children in the years ahead so that their education today can be better geared to meet the challenges and make good use of the opportunities that lie ahead.

Need for Caution

We see some danger of prejudicing the future of many deaf-blind children, particularly, the rubella children by precipitous action prompted by planning based on inadequate and unreliable information. There seems to be a fairly widespread tendency to accept the extremely rough estimates as to the size, composition, and distribution of the population of deaf-blind children as an adequate basis for planning facilities and programs to serve the needs of these children in the 1980's and beyond. It appears to us that these estimates are based, to a large extent, on hearsay evidence – reports of x number of deaf-blind children in a given geographic area, a particular hospital system, etc. We hear that there are 5,000 deaf-blind children in the United States. Yet, we have never had any indication that an unduplicated list exists of 5,000 names and addresses of children who have been determined or even judged to be deaf-blind on the basis of any widely understood, let alone, widely accepted, criteria of deafness and blindness. We don't know whether even minimum demographic data is available on any substantial portion of the 5,000 children that are reported to be deaf-blind and we are certain that ophthalmological or optometric and otological or audiological data is not available to establish the deafness and blindness of these children.

Our comments in the foregoing paragraph are not intended to imply any criticism. We hope they may serve to point up the advisability of working toward the development of specific objective criteria for determining who is deaf-blind and of accumulating sufficient reliable data on deaf-blind children – as well as on deaf-blind adults – to provide a sound basis for long-range planning.

Programs and Facilities

We believe that there is time to gather more data, to do more thinking, and to explore the extent to which existing programs and facilities can be used to meet the needs of today's deaf-blind children when they become adults. Very likely, most of these children will be found to be deaf-blind as a result of the 1964-65 rubella epidemic. This means that they will be only fifteen or sixteen years old in 1980. It has already been determined that many of them will require total custodial care for the rest of their lives. A number of them will be found to be capable of entering fully competitive employment including, in some cases, technical, professional, or administrative work. The challenge of this latter group will have to be met on a highly individualized basis and will tax the imagination, ingenuity,

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1. National Society for Prevention of Blindness, NSPB Fact Book, New York: National Society for Prevention of Blindness, Inc., 1966.

energy, and faith of everyone concerned in their education and rehabilitation. It is the intermediate group, with capacities that range from extreme inadequacy for any significant degree of independence to adequacy for a high degree of independence in an adapted environment offering appropriate help for whom fairly broad special provisions will have to be made.

Many of the children in the intermediate group will present major educational problems. We hope that the schools and other educational programs that serve them will resist the temptation to avoid these problems by giving up too soon on the children who present them or by moving these children into rehabilitation programs too early. The educational setting, which is typically available to a child, over a period of twelve years or more and which offers an opportunity to coordinate teaching with emotional and intellectual readiness for learning during the various stages of an individual's basic development, affords opportunities for teaching and training which, if not used, will never be available to the same degree in adulthood. We all need to remind ourselves that ineducability, untrainability, and nonfeasibility for rehabilitation reflect not only the limitations of the individuals who suffer from these conditions, but, equally, the inadequacies of the individuals and programs available to serve them. Those whom we cannot serve adequately present us with the greatest challenge to improve our ability to serve and should be retained in our programs as long as possible for their sakes as well as for the opportunities they afford us to improve our knowledge, our skills, and our programs.

The experience of the National Center demonstrates that many properly trained deaf-blind adults can be well served by existing sheltered workshops and work activity centers. It may very well be that residential work activity centers or some sort of similar programs which will combine work with continuing reinforcement of rehabilitation training on a very long-range or permanent basis will prove to be required for low-functioning deaf-blind people who do not need and who are damaged by total custodial care over a protracted period of time. Before building facilities for such programs, we might do well to determine the availability of unused or under used facilities that could be adapted for use in serving low-functioning deaf-blind people. Even if it proves advisable ultimately to build special facilities for this purpose, we think, based on our experience at the National Center, it would be desirable to use borrowed or rented facilities temporarily to afford an opportunity to acquire the kind of experience that will indicate what might be required in the location and design of the facilities to be built for permanent use.

In planning a program to provide limited employment for severely handicapped, low-functioning individuals, there are considerations that are too often overlooked which can make the difference between success and failure in the program. In addition to studying the composition and distribution of the group to be served, the kind of professional and technical services that will be required to meet their needs, and the kind of environment that will be likely to be conducive to good emotional health for the group, it is important to determine what kind of work they can produce within their limited capacities that is likely to be of salable quality. Marketing research to determine the availability of suitable subcontract work and the size and location of markets for products that might be produced by the group to be served should be used to provide important input for planning the location, size, and equipment of any facility to be designed to provide residence and employment for any severely handicapped group.

Closing Comment

We are very mindful of the fact that every participant in the meeting for which this paper has been prepared will be expected to read the papers of all the other participants. We have tried to touch on a number of subjects that we think might be profitably discussed at the meeting without trying to fully develop any of these subjects. This effort has been our contribution to the objective of keeping the reading required to prepare for the meeting to a minimum. We are afraid that we have fallen short of meeting this objective well; but we hope that we have produced a paper that will warrant, at least, a quick perusal and that will result in some discussion from which many of us may benefit.

The Current Status of Programs for Professional and Para-Professional Special Education in the Colleges

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Teacher Training Programs

During the 1972-73 academic year, seven colleges and universities graduated one doctorate, one educational specialist, thirty-six master's and eight bachelor's degree teachers plus twelve certification only teachers of deaf-blind children. In addition to these, there were sixteen master's level and one post-master's who completed programs in the education of the severely handicapped, not specifically the deaf-blind, and nineteen master's level graduates of programs for the severely handicapped child of preschool age.

The number enrolled in preparation programs for the deaf-blind during the current year includes six doctoral students, one educational specialist, one hundred and eighteen master's, ten bachelor's and forty certification only students. This should not be interpreted to mean that there will be a gigantic increase in the number of graduates this year, as some programs are more than a year in length and the number also includes part-time students who may require several years to graduate. It seems probable, however, that the number who graduate will be at least double that of last year. The number of graduates of other programs for the multihandicapped and those for preschool multihandicapped may also be expected to double in numbers of graduates.

The above numbers refer to students in eleven colleges and universities, most of which are now at full capacity in these programs. However, several additional institutions are in the process of beginning programs for teachers of multihandicapped children. One of these is being developed by a person with specific training and experience as a teacher of deaf-blind children.

In-Service Training

In spite of the dramatic increases in the numbers of pre-service graduates of special programs and in the number of institutions of higher education offering this type of personnel preparation, it seems probable that there will continue to be a need for increased in-service training in the various educational delivery systems and in colleges and universities, whether funded through the regional centers, state education agencies or the institutions of higher education. In addition to in-service programs for those who have been employed without special training as teachers of deaf-blind children, there will also continue to be a serious need to provide programs for up-dating previously trained teachers.

Much in-service training occurs spontaneously, as in the case of the team of experts in the areas of speech and hearing, visual handicaps and others who share their knowledge and techniques. It may be assumed that ideally every team serving deaf-blind children would have at least one member who has had training as a teacher of the deaf-blind. Even with the increased number of graduates of these special preparation programs it seems unlikely that this will become a reality in this decade.

Preprofessional Training

The shortage or lack of personnel with any training or experience in working with deaf-blind children appears to be most acute in institutional settings. A special project being undertaken by one regional center should provide some improvement in these situations as well as in settings where additional staff members are needed to complement the work of more highly trained teachers. Students with majors in special education from colleges near institutions and other settings where there are or may be programs for deaf-blind children will be given an intensive summer practicum with deaf-blind children as a pre-service training experience, to be followed by close supervision in either a job or an internship experience.

Paraprofessional Training

Since the Division of Personnel Preparation is now funding programs in community and junior colleges, a more qualified group of paraprofessionals should be ready to assist in all types of settings. The type of training might include daily living skills and orientation and mobility within a restricted environment such as an institution, or training to assist in developing pre-vocational or vocational skills, or to serve as recreation aides.

Pre-Vocational and Vocational Training

Those involved with personnel preparation of teachers of deaf-blind children have begun to provide the students with experiences in pre-vocational and vocational programs for multihandicapped children and youth, where such exist. One or two have added some emphasis on this aspect in their preparation programs. However, the demand for the graduates to work with children, many of whom are functioning on a preschool level, is so great that the greater emphasis continues to be on motor, social, language and cognitive development, and behavior management. It has been suggested that these teachers might be retrained to provide vocational training to older deaf-blind children. This may prove possible for some, but it seems more probable that they will continue to serve children functioning on a younger level. This seems especially probable since many of the facilities in which they are now working with deaf-blind children also serve other severely handicapped children for whom many of the same teaching skills are needed. For those who choose to work with older deaf-blind children in developing pre-vocational and vocational skills and further skills in independent living, special programs for retraining will need to be developed. It is possible that they may be joined by others from other areas of special education where there may be surpluses in the near future. Unfortunately, there are few models on which to build programs to prepare personnel for vocational education for the handicapped. Despite the declaration of career education and vocational education as priorities with the U.S. Office of Education and specific statements regarding this by the Division of Personnel Preparation of the Bureau of Education for the Handicapped, only four programs have been identified as especially directed to this purpose, two of these having been granted to state education agencies. . . tailor-made to their state vocational education patterns.

Development of New Programs

Judging from experience with the personnel preparation programs which have been developed thus far, it seems wise to consider that new programs should be geared to serve severely multihandicapped children including the deaf-blind rather than exclusively the latter. This would enable the establishment of larger programs with several faculty members with a variety of backgrounds to contribute to the students. The problem of beginning new programs or redirecting established ones should not be as great as was experienced five years ago when there were only two preparation programs for teachers of the deaf-blind, each serving the neighboring residential school that mothered it. There is the opportunity of profiting by the experience of establishing early childhood personnel preparation facilities, and there is the recognized need for teachers of severely handicapped children and youth brought about by new state legislation and litigations. Fortunately, there is experience that tells how it can be done. There is no question about when . . . 1980 IS NOW.

Characteristics of the Population

Potentials of Rubella Deaf-Blind Children

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Ten years have now elapsed since the dark days of the 1964-65 rubella epidemic. We are now able to sit back in sober fashion and measure some of the consequences. One of the most serious of these consequences and the one of greatest concern to us here is the estimated population of 5,000 children born in this epidemic who have both hearing and visual defects or, in other words, who are deaf-blind children.

Thanks to the tireless efforts of many people, professionals, parents, and lay persons, and to a sympathetic and responsive Congress, a large percentage of these deaf-blind children now find themselves in stimulating programs designed to develop their human potentials. However, the potentials of children who are visually and auditorially impaired from rubella are not easily understood by the casual observer or even by those of us who have been working with them for the last ten years. As if the deafness and blindness of these children were not enough to tax our understanding, we quickly discover that large numbers have additional complicating handicaps. Many are mentally retarded, some of them severely so. Many of them seem to demonstrate some form of perceptual dysfunction beyond the deafness and blindness. It is as if the same destructive force that damaged hearing and vision, also, in a fiendish way, scrambled the circuitry on the switchboard of the central nervous system. Perhaps related in some way to these factors already mentioned is the characteristic of emotional disturbance commonly found among these children, to say nothing of the emotional frustration that often appears in those who must care for them. If there is truth in the comments just recorded, it would seem most appropriate that we analyze and study the potentials of these children with a view of projecting both their needs as adults and the contributions they are likely to be able to make in our society.

Classifications

To classify deaf-blind children into groups is rarely appropriate and is often unfair to the individual for each child, even if he is deaf-blind, has his own individual characteristics, his peculiar strengths and weaknesses, and his own peculiar desires and goals. Yet, for us to understand in broad terms the scope of the problems we face with deaf-blind children, it seems necessary to distinguish some broad groupings. Let us for the sake of discussion, therefore, identify three of these broad groupings and then go on to consider the potentials represented within each group. We must remember, of course, that the boundary lines between these groups are vague and flexible and that there can be overlapping as far as particular characteristics of individual children are concerned.

For the purpose of this discussion, let us use these classifications:

1. Middle trainable and below
2. Upper trainable through lower educable
3. Middle educable and above

This author has a mistrust of formal intellectual measurements made in terms of IQ's. We have adolescent deaf-blind children who have been unable to advance beyond a primary level in academic scholarship and who, therefore, might be considered to be at the lower levels of the IQ range. Nevertheless, they have been able to function in independent living and to reach a degree of vocational success expected only of handicapped students within the normal range of IQ. Let us, therefore, use terms that express practical functioning levels.

Middle Trainable and Below

Almost everyone seems to agree that of the estimated 5,000 deaf-blind children before us, the largest percentage of them would fall in this lowest functioning class. Undoubtedly, there will be disagreement as to the size of the percentage in this group but until we have more complete and accurate statistics, we can only estimate the numbers within it. From observation, from correspondence and from discussion with others, this writer would guess that the percentage of somewhere between sixty percent and seventy-five percent would be near the truth. A number of this group, of course, are to be found in institutions for the mentally retarded, and appropriately so, or in a similar setting because these children are completely dependent on others and probably will be so for the rest of their lives. A number in this group are being given stimulating training programs in residential settings outside of the institution and still others are being trained in a day class setting and being housed with their families or in foster homes. Because of the low functioning level of these children and often because of their restless, hyperactive nature, families in foster homes find these children most difficult to tolerate. Many have tried gamely to adapt themselves to the needs of the child only to collapse under the constant, long-term pressure. Others have made a successful adaptation, but often at a great sacrifice to the integrity of the entire family. Certainly family involvement in the lifetime careers of these severely handicapped children is to be desired and sought, but in the total career programming for these young ones, there must be some recognition of the fact that there will have to be other facilities available to share with the family their responsibility for these quite dependent deaf-blind persons.

But this suggests that this lowest class of deaf-blind young people has very little potential. If considered in a relative sense, this is not necessarily true. Certainly very few of them will be able to undertake competitive vocational effort. Probably only a few will be able to make nominal contribution in a sheltered workshop. Some will be able to tolerate and perform simple, repetitive tasks under supervision for periods of time. On the other hand, in terms of developing skills that will reduce the burden upon those about them, let us examine some of the areas of potential development for this low functioning group of deaf-blind children. The following comments, of course, are predicated upon the existence of a structured and stimulating training program for them.

COMMUNICATION SKILLS

In general, this group of children is likely to be limited to very basic gestures and signs developed on the basis of direct conditioning. For those at the lower level of the group to make known their toilet needs, their hunger and thirst demands, and their comfort and discomfort may become the limit of their communication skill. From the middle to the upper levels of this group, however, we may expect a more extensive repertoire of signs and gestures. Most of the concepts present in the communication interchange will be very concrete and related to a large variety of daily living activities. Also, the degree of vision of the individual and the degree of hearing of the person will have considerable bearing upon how extensive and how effective the communication process becomes. Within the upper segment of this group and within the concrete gesture and sign framework, the frontiers of communication may be limited only by the imagination and resourcefulness of those instructing the children. As these children grow to adulthood, we may be astonished at their capability for acquiring a variety of useful concepts within the communication area. The primary caution must lie in their continuing need for close and direct supervision since most of them will lack the judgment or the sophistication to take advanced action without it.

DAILY LIVING SKILLS

Again, at the lower levels of this group, we can expect very little progress in the acquiring of independent living skills. Some of these children have been and will continue to be bed patients and major goals may be to learn to sit and to walk. However, a considerable number at the middle and upper levels of the group may be expected to acquire a high degree of independence in living skills by the time they have become adults. This will include toileting, dressing, feeding, and personal grooming. For a number, it may include making beds, keeping the room in order, clearing dishes from tables, assisting with dishwashing and laundry preparation, and similar chores. Again, one important key to success with this group of clients will be the resourcefulness of the supervising adult and their constant presence on the scene.

MOBILITY AND ORIENTATION

Once again, at the lower levels of this group, a prime objective may well be the ability to sit and to stand and to move under direction from one place to another, and some of the clients may never acquire these basic skills. On the other hand, as we move up into the middle and upper levels of the group, considerable potential may be found. In combination with satisfactory communication concepts, independent movement within a well-defined and known physical environment will be acquired by many. It is unlikely, however, that many of this group will acquire the judgment or the skill to travel freely and unsupervised in the complex framework of a community. If they are able to do so, the chances are they will have proven to have greater ability in all areas of function and will have moved up into a higher group in terms of potential. On the other hand, it may be expected that many of these lower functioning persons may come to recognize and to respect limits on their mobility beyond which distress or even danger may be expected.

VOCATIONAL EFFORT

The vocational future for this group must be considered very bleak, indeed. For those in the middle to lower level of this range handling their personal grooming and assisting in some of the household chores may have to be considered their vocational contribution. Others at the upper levels of the group may be able to perform some simple repetitive hand tasks either in their residential settings or in adjoining sheltered workshop. Very structured and carefully supervised procedures will need to be followed to result in any vocational success.

SELF-CONTROL AND SOCIAL INTERACTION

Here perhaps is the most significant area of all for our attention as it relates to this low functioning group of deaf-blind persons. The control they are able to acquire of body, attitude and emotion and the way in which they are able to interact with others, free of conflict and comfortably, cheerfully and considerately will have much to do with their ultimate contribution to our society. For a number in this group, and not necessarily those at the lower level, this type of control of body, of emotion or of social interaction may be unobtainable. For this number, direct and most certainly exhausting control by assigned staff, perhaps in an institutional setting, may be necessary. On the other hand, a large number of this group, in the opinion of this writer, may be brought to the satisfactory level of body control and happy social interaction with others through a prolonged and carefully structured program of training. Many of these children will respond satisfactorily to conditioning and to consistent handling under behavioral modification. Certainly, if this type of training can help a significant number of them overcome their hyperactivity and variety of socially offensive sounds, body movements, and other physical habits, then it is well worth the investment. This potential within the group and the training program to develop it may well make the difference between the need for complete institutionalization and the possibility of a less restrictive living setting.

SUMMARY

From the foregoing consideration of our lowest group in potential, two or three general conclusions seem to emerge. In the first place, a significant number of this lowest group have very limited potential indeed and will probably need throughout their lives some form of enlightened, institutionalized direct care. Secondly, a rather large segment of this lowest group has considerable potential for independent life style within a trainable format. Thirdly, the development of this potential will be extended most effectively by the imagination, resourcefulness and consistent application of the staff directing the training program. Fourthly, the potentials present in any individual within this group do not always at once reveal themselves. Under the stimulation of an effective training program, some of these children may well show the potential enabling them to rise in performance into the next higher grouping.

Upper Trainable Through Lower Educable

The percentage of our 5,000 deaf-blind children falling in this group is much smaller than that for the previous lower functioning group. This writer would estimate the percentage from fifteen percent to twenty-five percent of the total, although history may record that the percentage will be higher because of the elevation of some of those from the lower group due to effective programs. Although the numbers in this group are fewer, the degree of potential for training is considerably greater and at the upper limits can approach almost complete independence. Yet, a number of the deaf-blind children in this group display or have displayed some of the same characteristics found among children in the lower group. Hyperactivity and emotional disturbance of varying degrees are common. Patterns of perceptual dysfunction defined in this group as varying forms of learning disability are often present. However, in general, there is a greater capacity within this group to overcome these problems through consistent, well-structured training. Perhaps this is because success more readily follows in the wake of effective training with these children. Let us look more closely into the specific potentials for the children in this group.

COMMUNICATION SKILLS

In general, the members of this group respond reasonably well to the total communication process and, at the upper limits of the group, often surprisingly well. Almost all will use effectively at least the rudimentary gestures and signs necessary to meet their daily needs and many will acquire this language at a more sophisticated level and will communicate swiftly. Particularly from the middle to the upper level of this group, language can develop to the point of being expressed by effective fingerspelling. Reading and writing of the printed word may follow, and in some cases may be expected to reach up into the fourth, fifth, or even sixth grade level of performance. A number, of course, will not reach the sophistication of significant reading and writing skills and many will be able to receive and understand the language of communication better than they can express it. Here and there a child in this group may acquire some speech, receptive and expressive, but in general this group is not likely to be highly oral. Again, the degree of residual sight and hearing can make a great difference in performance. If considerable hearing is present, then a great amount of oral language may follow. If there is a great deal of sight, then written language will be facilitated. If there is a good deal of both, then the child may not seem to belong in this group at all but rather in the next higher one, although this may be misleading. A serious problem arises in the communication process in these children. Except for those who may develop effective speech, all will have a form of communication which, although effective among those who understand this form of communication, can isolate them from others who do not understand this manual form. This is unfortunate and can serve to limit the entry of these people as adults into full relationship with others in the normal adult world even though their other potentials might entitle them to this entry. At any rate, this group of children is capable of acquiring effective communication skill with others and this potential should be exploited to the fullest.

INDEPENDENT DAILY LIVING SKILLS

In general, this group has a high potential for the development of independent daily living skill except for a few more who may have additional physical or orthopedic handicaps. All of this group should be able to gain complete independence in dressing and grooming, in feeding, and, perhaps, in the preparation of their food, in general housekeeping skills, in the purchasing of necessary goods and services, and in the budgeting of their funds. Some of those at the upper limits of this group who have a great amount of useful vision should be able to acquire almost complete independence in their living styles as adults. Others who do not have this degree of useful vision will require varying degrees of supervision and guidance. Most of those at the lower levels will undoubtedly need some type of supervised group living setting or family or foster home direction. However, almost all of the members of this group should be able to make a significant contribution to the maintenance of themselves and others in whatever group living setting they find themselves. This is, of course, contingent upon a thorough and consistent training program during their growing years.

MOBILITY AND ORIENTATION

Again, in this group of deaf-blind children, we should expect potential for considerable understanding of the process of independent travel and for the assumption of a good deal of responsibility in relation to it. This, however, is not to suggest that all of these people by the time they are adults will be able to travel independently or that even a large number of them will. Many of those from the middle to the upper level of the group who have sufficient useful vision and/or hearing will be able to travel quite freely. Those who do not have this degree of vision, however, will be dependent upon others for the travel process beyond the limits of the familiar environment where no serious traffic hazards exist. More important, however, a large number of this group should be able to understand the limitations placed upon their independent travel and learn to live graciously within these limitations. Even for the less able members at the lower level of this group, independent travel within comfortable, safe, familiar surroundings should be attainable. This again presupposes a well developed and effective mobility training program for these children during their growing years.

VOCATIONAL EFFORT

Vocational effort at some level or another for almost all of the members of this group should be considered an attainable objective. True, some at the lower levels of the group and those who may have additional handicaps involving weakness of manual skill or coordination or continuing degrees of hyperactivity, emotional disturbance or other personality flaws may be able to acquire only minimal vocational success. The less able of the group may find their effort limited to day-activity center work. Others may find the sheltered workshop the limit of their attainable goal, but a considerable number at the middle to upper levels of the group should be able to find vocational outlet in competitive industry, in some type of business practice or in one of the many people-service fields. At Perkins School for the Blind, a few adolescent deaf-blind persons in this class demonstrated, under a concentrated training program, their ability to meet these suggested vocational goals. Again, the degree of vision and hearing that remains to the individual can make a significant difference in the degree of independence one can attain. The degree of independent travel and the skill of easy communication related to this degree of sight and hearing are important factors.

SOCIAL INTERACTION AND RECREATIONAL SKILLS

Most of the members of this middle group of deaf-blind children have the potential to develop the personal care skills and the social amenities necessary to make them acceptable in the adult world. Certainly they have ample potential to acquire normal social recreation skills. They can learn to roller-skate and to ice-skate, to swim, to play a variety of games, to bicycle tandem style, to hike, and to participate in a variety of social activities. Their difficulty in social adjustment is more than likely to rise, particularly for those with little vision and/or hearing, from their dependence upon others for safe travel and from their ineffective communication skill with others who do not understand their form of communication, if it is not oral. For many of the members of the deaf-blind persons in this group, these factors can place a strain upon their relationship with families, foster homes, and even others who share a less formal and casual relationship with them. A demanding manner, perhaps arising from frustration over the inability to be independent, can often be associated with these persons. The results can be distress and withdrawal on the part of the normal adult world. It is not that this group of deaf-blind persons lacks the potential for adjusting socially to the adult world but rather that they must have continuing, consistent counseling during their growing years. Thought must be given to adult living settings that will minimize the stresses and strains caused by their dependence in travel and their limitations in communication. Again, a number of the children in this group will find these problems minimal because of their considerable amount of vision and/or useful hearing.

SUMMARY

With this middle group, also, two or three general concepts seem to emerge. First of all, considerable potential for independence in many phases of life activity exists within this group. Those with considerable and/or useful hearing will often be able to make an independent adjustment to the world; those with equal mental and physical ability, but lacking the sight and hearing, will find this independent adjustment more difficult. Secondly, this group in general has far more potential for making an independent adjustment to the world in terms of practical, everyday living skills and a greater likelihood of making a vocational contribution to their support than their low attainment in formal scholarship or academic performance would suggest. It would appear that with these children skills related to language development and reading and writing are depressed, whereas with proper training experiences, attainments in the practical routines of everyday living need not be depressed as much. Thirdly, again it becomes obvious that the realization of the considerable potentials of this group is dependent upon an effective and consistent training program through the formative years.

Middle Educable and Above

The experience of this writer suggests that this group, unfortunately, is an extremely small one as compared with the other two groups, perhaps no more than five percent to ten percent of the total of 5,000. In fact, we seem to find very few of the rubella deaf-blind reaching this level of potential. Most of the members of this group appear to have received their handicapping condition from a source less devastating to other parts of the human organism.

Again, of course, degrees of residual vision and hearing play an important part in the development of potential. Emotional stress often seems present in the early developmental stages with these children, perhaps related to the frustration an active mind finds in its effort to penetrate the barriers placed upon it by blindness and deafness. However, achievement levels, both academic and nonacademic, are usually high and the concept-building process can be effective.

COMMUNICATION SKILLS

Not all but most of the members of this group are able to master oral language. Many in the early stages quickly learn the basic gestures and signs of the communication process and under proper instruction are able to advance into the oral mode. This is an important capability for these people because it enables them to communicate directly with people who are unfamiliar with the sign language of the deaf.

INDEPENDENT DAILY LIVING SKILLS

Except for those in this group who have additional motor or orthopedic handicaps, the mastery of satisfactory independent daily living skill poses no serious problems. Under a consistent and effective training program and one that includes counseling to help in positive attitudes, these children should become quite independent as adults as far as daily living and self-care skills are concerned.

MOBILITY AND ORIENTATION

Again, unless the child has a good deal of useful vision or a large amount of useful hearing, or both, he is going to be quite dependent upon others for any extensive travel. The members of this group will be able to master the techniques of independent travel in familiar and hazard-free areas without much difficulty, but beyond this rather narrow scope, they will be dependent upon others. They should, however, receive as complete training as possible to make them as free as they can be of dependency and also to provide them with an awareness of spatial matters.

VOCATIONAL TRAINING

Obviously, vocational success for this group is more promising than for most members of the other groups. The range of opportunity is greater and the training process is less complicated.

At the upper levels of this group will be a handful of persons capable of professional training and professional service. The problem here is not so much in providing training at the college level and beyond, but in finding the opportunities in which they can function once they have received their training. It is difficult for an administrator to imagine employing a person who is blind and deaf. Yet, a number of deaf-blind professionals have proven that it can be done. Rehabilitation and guidance counseling of both normal and handicapped clients is a possible career. Teaching is also a goal that can be reached by some when thought of in the proper setting and dealing with the appropriate students. Self-employment in business enterprise in a few cases has been found productive.

Unless the members of this group have additional handicaps involving motor function, the more advanced skill trades are certainly possible. Leonard Dowdy, who, though not a "rubella" deaf-blind person, has been totally blind and profoundly deaf since nineteen months of age, has demonstrated well the capability of a deaf-blind person in the operation of simple factory machines and advanced assembly operations. The ultimate boundaries in these areas for capable deaf-blind persons have not yet been been approached.

There are three factors which can stand in the way of success for deaf-blind individuals in this class. The first is their own lack of will and desire and other possible personality defects. The second is their failure to receive appropriate and effective education and training. The third is the unwillingness of employers to give them a trial or the lack of an effective placement service to assist them in finding their vocational niche. The same, of course, could be said for a number of the middle group of deaf-blind persons we considered earlier.

SOCIAL INTERRELATIONSHIPS AND RECREATION

Potential for success with other members of our society must be considered high for this group of deaf-blind persons. However, this success will not come without considerable effort on the part of the deaf-blind individual and of those who are educating him for the social encounter. The subtleties of gracious, unselfish "give and take" with others are understandings that do not come easily to one who is deaf-blind even though he be highly intelligent. During many of his formative years in the educational process, the deaf-blind child finds himself very much the center of attention without the benefit of vision and hearing to bring him the experience of these subtleties through direct observation. His inclination is to remain self-centered much longer than do most of the rest of us. Therefore, it is important to provide him with effective personal counseling at every step of his training.

Another serious problem facing these people socially arises from the difficulty they find in taking the initiative in making and maintaining social contacts. This difficulty is imposed by the limitations of the communication process. Usually, the deaf-blind person must wait for the other person to make contact before a social interaction can take place. Electronic devices attached both to the telephone and typewriter have helped to ease this problem but greater understanding on the part of nonhandicapped people and their willingness to take more initiative with deaf-blind people are necessary to bridge the gap.

Certainly, with an appropriate training program, the deaf-blind persons in this group can master almost all of the necessary skills for successful interaction. This includes a great variety of recreational skills which can serve as a framework for social relationships.

SUMMARY

The summary for this group can be very brief. Given a thorough and complete educational and training program, adequate adult rehabilitation support and an informed, accepting public, the percentage of successful careers among this group of deaf-blind persons should be high indeed.

Facilities and Resources

Before closing, let us take just a few minutes to consider some of the types of facilities and resources that may be desirable to meet the needs of these deaf-blind persons as adults. First, consider the lower trainable group which probably is by far the largest in number. Complete supervisory care would seem to be the order for the future for most of the members of this group. Here and there a family may find within it the resources to care at home for one of these people as long as the family exists intact. This is likely to be rare over the long haul. Already too many families have been torn asunder by the presence of a seriously retarded deaf-blind child. To find satisfactory foster home placements on a permanent basis for these persons is equally unrealistic. Some type of group living with professionals who are both competent and sensitive to the human need will be necessary to serve these clients. There is nothing wrong with an institution even though it be separated from the everyday life of society, if it is enlighted and recognizes the integrity of the human being. Small self-contained cottage family units in a pleasant setting where the deaf-blind can be treated and encouraged to do everything possible for themselves and to help in the joint effort wherever it can be done would seem to this writer to be appropriate. We must not lose sight of the possibility, of course, that here and there a deaf-blind person at the upper limits of this group may, through a stimulating program, develop the ability to advance into a broader life style. This will be expensive as compared with the economic return that is likely, but we are still a wealthy nation and should have human value as our most important goal.

The outlook for the middle group is, of course, more promising for the future involvement of its members in our regular social order. A large number of this group will need considerable supervisory care but more because of the ineffective communication and limitations upon travel than upon inability to function in daily living activities and in vocational effort. Small community residences containing eight to ten persons in each would seem to be a model that could meet the needs of many. These residences, supervised by professionals, should enlist the cooperative effort of every member in the house maintenance. The program should provide for an intermingling of the house members within the community and include such matters as food shopping, social and recreational contact and vocational effort. There should be available to the clients of the residence for vocational purposes:

1. an opportunity for vocational tasks within the premises of the house itself,
2. a sheltered workshop within feasible travel range for those who may be able to participate in it, and
3. an opportunity for employment in open industry for those at the upper levels who may well be able to succeed in this way.

This writer sees these community residences as being of two forms. The first would be a residence made up of just deaf-blind clients and their supervisors. Many in this group will need this type of exclusive residence because of their inability to communicate easily except with other persons who understand gesture, sign language, and fingerspelling. On the other hand, a second type of community residence should be considered for any member of this group who is able to make a successful adjustment in communication and can take effective initiative with persons who are not deaf-blind. These deaf-blind individuals might well join a community residence for other types of handicapped people and in this way broaden their life style.

We should not overlook the possibility of individual placement for some members of this group. Many of these persons, particularly at the upper levels of this middle group, can be absorbed into a family or foster home setting and succeed adequately if they have had proper education and training. Great care must be given, however, to making certain that the individual is truly prepared for this type of life style and that the family or foster home has adequate support to make the relationship a successful one. There may be a few members of this group, particularly those who have some useful sight and/or hearing, who may be able to live independent lives, to marry and to have a family. The important thing is that we raise up in the next few years a cluster of experienced, sensitive professionals who are able to understand the needs of these deaf-blind individuals and of society and who have the energy and resources to fit the two together.

It is the conviction of this writer that this group as a whole, if handled in a way similar to the process just suggested, can be almost independent, can be self-supporting, can make a contribution to our social order, and can have in return enriched and fulfilled lives that will be well worth the efforts we make.

In the small group of higher functioning deaf-blind rubella persons, there should be a greater concentration on establishing individual home and family placements. If we play our cards properly, this group should be productive and successful and should be helped to find opportunities for complete family living. This may be within marriage and family life for some. It may be in a foster home for others. It may be in a professional community residence for still others. Certainly, in a community residence, there should be an effort to desegregate the deaf-blind wherever communication skills make this possible. If a sizable number of this group finds itself relegated to a sheltered workshop, we will have missed our mark. If a significant number of the highly trained professionally capable persons find themselves unemployed, we will also have missed our mark. This is a small population and certainly we can find the resources and the dedicated professionals to give a concentration of effort toward the success of every member in it.

The General Public

Now let us consider one last topic, in some ways perhaps most important of all, the role of the general public. We can prepare our deaf-blind clients as completely as it is possible for them to be prepared in communication skills, in travel and mobility, in vocational skill, and in social processes and still fail our clients. If at the end of the process the general public is both deaf and blind to the needs of this group of people, much must be done to inform, to arouse the interest, and to solicit meaningful involvement in programs for deaf-blind persons. We cannot expect to operate a successful community residence for a group of well-trained and well-qualified deaf-blind adults if the people in the community are going to resent their presence, shun contact with them or just stand by passively and watch them with curiosity as they move in and out of the community. A little effort on the part of many, many human beings can serve to bring rich fulfillment to the lives of our deaf-blind clients. Many people are perfectly willing to involve themselves but are anxious and fearful concerning the encounter. Other "do-gooders" will plunge in in the most inappropriate way and cause equal anxiety and fear on the part of the deaf-blind clients. At every local level where deaf-blind persons are, and this should be a highly decentralized process of living, there should be active campaigns to arouse the public to the need and to positive action.

Beginning with the rubella epidemic in 1964 and 1965, our social society was presented with a challenge to prove whether or not this society has reached a stage of enlightenment in human understanding and has come of age spiritually. The Congress of the United States demonstrated this enlightenment by voting the necessary funds. A large number of professionals have rolled up their sleeves in response to the challenge and have made remarkable progress. It now rests with the Congress and the professionals to enlist the full support of our entire society to make the final proof conclusive.

Legal Aspects

Basic Legal Aspects of Planning for Deaf-Blind Persons

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The purpose of this paper is to place into perspective recent developments in the law which affect handicapped persons and explore how the law may influence planning for deaf-blind persons.

After a few brief notes on the role of law in the planning process, a suggested statement of rights of deaf-blind persons will be presented. Recent legal action concerning education, habilitation and treatment will be summarized to illustrate legal principles of due process and equal protection as applied to handicapped persons. Finally, the elements and characteristics of a sound legal framework for planned programs for the deaf-blind will be explored.

Law and Long Range Planning

Serious long range planning for the social welfare and individual well-being of a specific population of handicapped persons has not been undertaken often in the United States. In most state and federal programs, despite claims to the contrary, planning for future client needs takes a back seat to meeting current operational priorities. The planning that does take place, with few exceptions, is organized around and focuses on the goals, objectives and activities of discrete service systems rather than on the future needs of a particular population to be served. As a result, plans tend to focus on incremental changes in existing health, education, rehabilitation, employment, and income maintenance systems, highlight the potential of domain expansion within these systems and ignore the interface among service delivery systems, and the possibility of developing completely new systems for persons with complex and varying needs throughout life.

Even more rare in the planning context is the consideration of the law as it affects a specific population of handicapped persons. The idea of planning for legal change in concert with planning for program change has been overlooked; much to the detriment of planners, legislators and handicapped persons themselves. The dynamic interrelationship between law and program planning has been underestimated.

Traditionally, the law has been looked upon as simply a repository of social policy reflecting an amalgam of public attitudes about the handicapped – attitudes which range from concern, compassion, and some sense of community acceptance to pity, isolation and rejection. Since statutes and rules of law are not discarded or modified as readily as scientific and social theories, there is a belief that the law lags behind by necessity, its confusions and contradictions an appropriate reflection of fluctuating social norms. From this reasoning it would then follow that the legal framework governing and regulating public programs for the deaf-blind or other handicapped persons is a matter for lawyers and legislators to take up after plans and programs are developed.

This view of the law as a passive receptacle and implementation mechanism may have some historical validity; however, it should be summarily rejected as a guide for planning. While it is true that effective legal change requires changing public attitudes and political consensus, these factors also attend to successful program planning and development. A truly comprehensive planning effort is one that takes into account the pervasive and active interplay between the law and current and planned programs. On one hand, the planning process can synthesize experience, practices, research, and trends in a number of specialized fields to bring about new understandings of the deaf-blind population which in turn can lead to social and political action and program advances on behalf of the target group. On the other hand, it is the law which influences and determines the extent to which deaf-blind and other handicapped persons benefit from new understandings and program advances. It is not simply that legal action in the legislative or administrative and judicial arenas continuously impacts upon the lives of all handicapped citizens, but that a viable legal framework is essential to the successful implementation of new approaches to programs for deaf-blind and other handicapped persons.

Legal Framework

It should be recognized that when we speak of the law in the context of planning for handicapped persons, we are not exclusively concerned with legislation governing programs for the handicapped or the case law which specifically pertains to deaf persons, blind persons or other handicapped persons. We are concerned about all aspects of the legal process which affect handicapped persons, including laws which regulate or fail to regulate private relationships of handicapped persons (e.g., private contracts); laws which govern accountability and liability of service providers and caretakers; laws which govern domestic relationships; laws which subject persons to governmental processes, criminal or civil; laws which affect personal rights such as right to privacy, right to travel, right to association and religious liberty, and laws which define public responsibilities in generic programs such as education, rehabilitation, employment, transportation, medical care, housing, and economic security. Moreover, it is important to realize that legal developments having significant impact on handicapped persons, may occur without any reference to the handicapped. For example, a Supreme Court decision on public school financing may provide legal theories to facilitate equal access to education for handicapped children. A decision upholding restrictive zoning ordinances may foreclose the development of innovative residential alternatives for handicapped persons. Litigation on affirmative action in racial employment discrimination cases may be applicable to employment discrimination against handicapped persons. On the legislative front, enactment of comprehensive national health insurance or termination of the legal services program would affect handicapped persons to a greater extent that many changes in specialized legislation for the handicapped.

While general legal trends and the legal process in total are of considerable importance to deaf-blind and other handicapped persons, specialized laws and legal mechanisms applicable to certain classes of handicapped persons deserve in-depth examination. These laws may be divided into two categories:

1. those laws which provide the legal framework for specialized benefits to classes of handicapped persons, and
2. those laws and legal rules which single out classes of handicapped persons and impose restrictions on the exercise of many rights and privileges of citizens.

Within the first category, a person defined under law as handicapped may be eligible for residential care, preschool training, day care, special education, extended rehabilitation services, occupational training, employment preferences, or special welfare benefits.

Within the second category under the law, a handicapped person may be excluded from public schools, disqualified from voting, prohibited from contracting marriage, subject to sterilization, discriminated against in adoption, denied licenses of various kinds, and excluded from public benefit programs.

The question of how classes of handicapped persons are defined and identified under law for both restrictive regulatory purposes and program benefit purposes is itself an important legal issue and one that is particularly salient in the case of multihandicapped persons such as the deaf-blind. Two aspects of this problem are worth noting. Firstly, those legal schemes which fail to acknowledge the existence of multiple handicaps and thus sanction perverse outcomes in services to the handicapped (e.g., specialized programs for the deaf, specialized programs for the blind, specialized programs for the mentally retarded, all of which exclude the blind-retarded person, the deaf-retarded person or the deaf-blind person). Secondly, in the matter of definition, there exists some legal tradition of confusing communicative and sensory disorders with intellectual defects and mental handicaps and consequently applying identical provisions to the blind and deaf as to the retarded and in some instances as to the psychotic person. This issue and other aspects of how handicapped persons are singled out and under the law will be more fully explored in a review of current legal action and trends relating to the handicapped. However, in order to put both past legal developments and current legal action in perspective, it will be helpful to set down in some detail a statement of the human rights which should be guaranteed under law to all handicapped persons.

Legal Rights

Simply stated, the deaf-blind person, or any other handicapped person must be assumed to have full human and legal rights and privileges. Prosser states the general legal principle, "The man who is blind or deaf or lame or otherwise physically disabled is entitled to live in the world." Yet, the concept of equality before the law and the standard application of general legal principles assumes a minimum capacity to conform to the law and to invoke legal protection. Deaf-blind persons will vary in capacity to assert their rights under law and many will be at a disadvantage. For those persons, society must compensate and provide additional protection but must do so consistent with conditions least restrictive to personal liberty.

The most important principle underlying the development and protection of human rights of deaf-blind and other handicapped persons is that deaf-blind persons are individuals with individual characteristics. Like other persons, they differ in their skills and weaknesses. Also, like other persons, they will not remain static but, through life, will regress or undergo growth and development depending upon life experiences. It is a challenge to the law and legal institutions to develop mechanisms which recognize the developmental aspects of disability, take into account the variability of handicapped persons and at the same time formulate general principles which will protect and provide for deaf-blind persons as a class.

The protections of the U.S. Constitution and Bill of Rights as extended to all citizens through the due process and equal protection clauses of the Fourteenth Amendment are, when correctly applied, more than adequate to instruct us as to the rights of deaf-blind persons or other handicapped persons. However, when our concern centers on a small, vulnerable, politically powerless minority, such as the deaf-blind, it is useful for our own guidance and clarity of purpose to articulate as carefully as possible those human rights, entitlements and protections which are to be accorded to deaf-blind individuals.

There is a *caveat* which must accompany a statement of rights. In the last decade we have been exposed to much rights rhetoric. The vocabulary has become common; so familiar that we cease to contemplate the real meaning of human and legal rights, especially in regard to the correlative duties we impose upon ourselves as we espouse rights of others. Many of the rights set forth below can be found in the preambles of legislative enactments, resolutions and executive proclamations concerning handicapped citizens. Yet, rarely, are these rights fully incorporated in the goals, objectives and administration of programs which bear most heavily on the lives of the handicapped.

Statement of Rights

The following seven points are based on a resolution adopted in 1971 by the General Assembly of the United Nations on the rights of mentally retarded persons. The resolution derives from the work of the International League of Societies for the Mentally Handicapped and a declaration formulated by the league in Jerusalem in 1968. It builds upon the Universal Declaration of Human Rights, the U.N. Declaration of Rights of the Child and the U.N. Declaration on Social Progress and Development. The statement is paraphrased below to make specific reference to deaf-blind persons. Each principle could be applied to any or all classes of seriously handicapped persons.

1. *The deaf-blind person has the same rights as other human beings.*
2. *The deaf-blind person has a right to proper medical care and therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.*
3. *The deaf-blind person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.*
4. *Whenever possible, the deaf-blind person should live in a family environment and participate in different forms of community life. The family with which he lives should receive assistance. If care in a congregate facility becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.*
5. *The deaf-blind person has a right to a qualified personal guardian when this is required to protect his personal well-being and interests.*
6. *The deaf-blind person has a right to protection from exploitation, abuse and degrading treatment. If subject to criminal processes, he shall have a right to due process of law with full recognition being given to his degree of responsibility.*
7. *Whenever deaf-blind persons are unable, because of the severity of their handicap, to exercise all their rights or it should become necessary to restrict or deny some of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards including a plan for providing least restrictive conditions possible, an independent periodic review of restrictions imposed and right to appeal to higher authorities.*

With the above stated principles in mind, let us consider how recent legal action has influenced the development of a legal framework capable of protecting the rights of handicapped persons.

Recent Legal Action

In the last few years in the United States we have become more aware of the influence of legal and civil rights upon the ability of handicapped persons to achieve appropriate status in society. Building upon the experience and struggles of our minorities and disadvantaged, the handicapped and their advocates are now concentrating on enforcement of basic constitutional rights rather than, as in the past, relying on special legislative and administrative gratuities.

The thrust of a great deal of the advocacy activity on behalf of the handicapped in the U.S. in the last three years is embodied in the previously stated principle that a handicapped person has the same basic rights as other citizens. It is no accident that this principle clearly corresponds to the 14th Amendment of the U.S. Constitution guaranteeing equal protection under the law. In essence, when we speak of civil rights we are talking about treating people equally. In one of the earliest interpretations of equal protection, the U.S. Supreme Court held that all individuals "shall be treated alike under like circumstances and conditions, both in the privileges conferred and the liabilities imposed." In regard to handicapped persons the principle of equality is much more easily espoused than applied. Our notion of equality must be tempered to accord with Justice Frankfurter's admonition that "there is no greater inequality than equal treatment of unequals." However, today judicial, legislative and executive officers in the United States are grappling with real meaning of equal protection in terms of rights to education, training, community living and employment.

Two areas have received greatest attention from the federal courts in the United States. One is education, which has been recognized as a basic right for handicapped persons, and the other is institutional and community treatment which must conform to constitutional standards.

A brief review of selected cases in "right to education" and "right to treatment" may be helpful to planners and administrators to develop plans which enable deaf-blind persons to secure due process and equal protection in all dealings with public agencies and private parties.

Right to Education

Pennsylvania Association for Retarded Children v. Pennsylvania was the first case in which a federal court explicitly recognized the concept of equal access to educational opportunity for handicapped children. This civil rights class action brought by *PARC* and thirteen mentally retarded children on behalf of all mentally retarded persons excluded from schooling directly challenged Pennsylvania statutes which denied education to mentally retarded deemed uneducable, or unable to profit from school, or to those persons not of a mental age of five or those outside compulsory school age. Expert testimony so overwhelmingly demolished the factual underpinnings of the statutes that a consent decree was negotiated in which Pennsylvania acknowledged its responsibility to provide free public education and training to all children. On May 5, 1972, the three judge federal court approved the consent decree and permanently enjoined Pennsylvania education officials and local school districts from denying or postponing a free public program of education and training to any of the Commonwealth's mentally retarded children. In its order, the court noted:

> *. . . all mentally retarded persons are capable of benefiting from a program of education and training; that the greatest number of retarded persons, given such education and training are capable of achieving self-sufficiency, and the remaining few . . . are capable of some degree of self care; . . . whether begun early or not, . . . a mentally retarded person can benefit at any point in his life and development from a program of education and training.*

Although *PARC* counsel set forth the constitutional grounds for the right to education when requesting a three judge panel and again when a school district challenged the jurisdiction of the court, the constitutional issues were left for resolution in a subsequent case, *Mills v. Board of Education of District of Columbia*. The *Mills* plaintiffs were classified as brain damaged, hyper-active, epileptic, mentally retarded, mentally retarded with orthopedic handicap, and on the basis of these labels excluded from District of Columbia educational programs. On behalf of all children who had been excluded or otherwise deprived of access to publicly supported education, the plaintiffs challenged their exclusion and the procedures and practices by which District of Columbia education and social service officials denied children public education. Basing its decision of the due process and equal protection clauses of the United States Constitution, the *Mills* court ordered that:

> *. . . no child eligible for a publicly supported education in the District of Columbia public schools shall be excluded from a regular public school assignment by a rule, policy, or practice of the Board of Education of the District of Columbia or its agents unless such child is provided (a) adequate alternative educational services suited to the child's needs, which may include special education or tuition grants, and (b) a constitutionally adequate prior hearing and periodic review of the child's status, progress, and the adequacy of any educational alternative.*

On the strength of the constitutional holding, the *Mills* court put the final nails in the coffin of the concept of uneducability making its ruling applicable regardless of degree of type of exceptionality and regardless of the fiscal impact on the school system. Part of the August 1, 1972 decree reads:

> *The District of Columbia shall provide to each child of school age a free and suitable publicly supported education regardless of the degree of the child's mental, physical or emotional disability or impairment. Furthermore, defendants shall not exclude any child resident in the District of Columbia from such publicly supported education on the basis of a claim of insufficient resources.*

As in *PARC,Mills* detailed the due process requirements which must be followed in placement, reassignment, or transfer among educational programs. Parents are entitled to advance notice of placement and reasons for placement; right to a hearing by an independent hearing officer, including right to legal counsel or other advocate, a record of the hearing, right to inspect records, present evidence, cross examine witnesses, and right to appeal.

Cases patterned upon *Mills* have been filed in at least thirty states. Favorable decisions have been rendered in Louisiana, New York, Wisconsin and Maryland. Before the close of the year, final action is expected in Tennessee, North Dakota, Colorado and a number of other states.

Some of these cases are based on state constitutional provisions and statutes; however nearly all rely to some extent on the equal protection and due process clauses of the Fourteenth Amendment. The constitutional doctrine has been best explained by Attorney Paul Dimond. He writes:

> *First, the unjustified exclusion of any child from all public schooling denies to that child the equal protection of the laws when the state makes the opportunity freely available to other children. Second, the operation of our unfair procedure in the stigmatization by public authority of any person or the denial to him of any public good denies the process due each person under the 14th Amendment. Such a stigmatization and denial is involved in labeling children as exceptional, retarded, or handicapped and placing them in a special class, or excluding them from schooling entirely. These two rights, equal protection and due process, merge to form the emerging constitutional right to an education which guarantees to every child a minimally adequate publicly supported educational opportunity.* (24 Hastings L.R. at 1093.)

Establishment of a clear right to education has great implications for those who are concerned with improving the capacity of the adult deaf-blind person to contribute to society in his work and in his daily life. The courts have rejected distinctions between training and education and have accepted a definition of education which goes beyond the narrow concept of schooling. To wit: "Education is a *continuous process* of developing *life skills* needed for the effective coping with developmental tasks and demands as well as with environmental tasks and demands." (Testimony of Ignacy Goldberg, *PARC* Hearing of August 12, 1971.)

A persuasive case might now be made that reasoning used in equal educational opportunity can logically be applied to vocational training, pre-vocational services and other habilitation services vital to optimal adult functioning.

Right to Treatment

Like right to education, right to treatment is a shorthand for a merger of rights guaranteed by the due process and equal protection clauses of the Constitution. The Eighth Amendment's prohibition of cruel and unusual punishment and the Thirteenth Amendment's guarantee of freedom from involuntary servitude have also been used to bolster the case for the creation of a right to habilitation and treatment.

The right to treatment emerged in cases challenging the confinement of civilly committed mentally ill patients. It was argued that if the need for treatment provides the rationale for confinement then the patient must actually be treated or released. This argument was given some recognition by courts in the District of Columbia, and Massachusetts in the mid-sixties, but had little impact on patients or mental health service providers until raised in *Wyatt v. Stickney* and applied to all mentally ill and mentally retarded persons confined in public institutions in the State of Alabama.

In regard to the mentally ill, Chief Judge Frank Johnson stated that committed patients "unquestionably have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition."

As to the residents of Partlow State School, it was held "the mentally retarded have a constitutional right to receive such individual habilitation as will give each of them a realistic opportunity to lead a more useful and meaningful life and to return to society."

Initially, the court ordered the state to develop a plan for treatment and habilitation. However, further relief was required by Alabama's failure to improve the conditions which expert testimony had shown to be inhumane and devastating to residents – conditions which were characterized by lack of safety, lack of privacy, malnutrition, exploitation of patient labor, solitary confinement, excessive use of restraints, inadequate staffing, lack of individualized programs, deterioration of physical and mental conditions, brutality and patient deaths. Therefore, to rectify these conditions and implement the right to treatment, the *Wyatt* court not only set down the general parameters of minimum treatment (i.e., a humane psychological and physical environment; a qualified staff in numbers sufficient to administer adequate treatment and individualized treatment plans) but also set forth in detail the minimum constitutional standards for adequate habilitation of the mentally retarded, and adequate treatment of the mentally ill. To monitor implementation and guarante. that residents are afforded constitutional and humane treatment, the court directed the establishment of a human rights committee and retained jurisdiction of the cases.

The *Wyatt* court just as *Mills* faced the funding question head on and indicated that lack of operating funds could not justify withholding habilitation. Chief Judge Johnson stated:

> *In the event, though, that the Legislature fails to satisfy its well-defined constitutional obligation and Mental Health Board, because of lack of funding or any other legally insufficient reason, fails to implement fully the standards herein ordered, it will be necessary for the Court to take affirmative steps including appointing a master, to ensure that proper funding is realized and that adequate habilitation is available for the mentally retarded of Alabama.*

The existence of a judicially enforceable constitutional right to treatment and the approach to implementation taken by Judge Johnson in *Wyatt* was rejected by another federal court in *Burham v. Department of Public Health of Georgia*. *Wyatt* and *Burham* have been joined on appeal before the Fifth Circuit. In *Welsch v. Likins*, recently decided in the U.S. District Court for Minnesota, Judge Earl Larson fully accepted the reasoning of Wyatt and found a right to treatment under the due process clause of the Fourteenth Amendment and under the Minnesota statutes. In other cases federal courts in New York and Massachusetts, while avoiding the question of the nature of a constitutional right to treatment, have granted relief in line with minimum enforceable standards. In these subsequent cases on institutional treatment rights secured and relief provided has applied to those persons admitted voluntarily as well as those committed. In addition to the aforementioned cases, mental health and retardation administrators are defendants in right to treatment suits in Nebraska, Illinois, North and South Carolina, Missouri and Tennessee.

While the right to treatment cases have arisen in the context of grossly substandard institutions for mentally disabled persons, the principles may be applied to any residential setting which restricts the personal liberty of residents. There is a growing body of law, in juvenile cases, adult corrections cases and other areas, recognizing a constitutional right to treatment for persons confined in various settings under State Authority. It is clear that this right entails more than caretakers and service providers doing the best they can within the limits of existing resources. As Judge Larson noted in *Welsch*:

> *. . .good faith is not at issue here. It does not suffice, therefore, to show that conditions have been upgraded, that the situation will continue to improve in the future, and that even more achievements would be forthcoming . . . . It is the Court's duty, under the Constitution, to assure that every resident . . . receives at least minimally adequate care and treatment consonant with the full and true meaning of the due process clause.*

Legal Rights Movement

Legal action on behalf of handicapped persons in the areas of education and treatment exemplify a broad trend toward litigation and judicial intervention relating to various service systems. Physically handicapped persons have secured judicial enforcement of their right to access to public transportation and public buildings. Favorable decisions have been rendered in regard to entitlement to minimum wage and classification and placement procedures for specialized services.

Litigation is being brought on employment discrimination and rights to community services.

Litigation and legal developments noted have caused reverberations outside the courtroom and have influenced state and federal policy makers. Judicial action on right to education, and treatment has caught the attention of state legislators as evidenced by a recent resolution of the National Legislative Conference to develop model legislation relating to the needs of developmentally disabled persons, taking into account the role of institutions, education and community programs. More concrete examples are the hundreds of bills promoting education of the handicapped enacted into law by state legislatures during the last three years. Tennessee and Massachusetts have enacted comprehensive laws codifying many of the principles and rights enunciated in *PARC* and *Mills*. Implementation in North Dakota, Michigan, and Wisconsin is proceeding with an assist from potential or pending litigation. In treatment, Massachusetts is implementing its completely revised mental health, mental retardation code, while at the same time under court order to provide habilitation to institutionalized mentally retarded. In Ohio and Florida comprehensive codes incorporating a statutory right to treatment have been drafted and are before the legislature. Illinois, Indiana, Texas, South Dakota and a number of other states are in the process o completely revising their mental health and mental retardation codes.

At the federal level the influence of the legal rights movement is reflected in both Congressional and Executive action. The Rehabilitation Act of 1973 (P.L. 93-112) is an important step in the movement toward the concept of habilitation and rehabilitation as an entitlement. The legislative history of the act shows a clear concern for client advocacy and client participation in rehabilitation plans. Title V is replete with new tools for advocates to assert rights to employment and access to transportation and buildings. Amendments to the Civil Rights Act of 1964 to specifically protect handicapped persons from all types of discrimination has been urged by Congressional leaders, and a "Bill of Rights for the Retarded," incorporating the standards approach of *Wyatt*, has broad-based sponsorship in the United States Senate. H.R. 70, S. 6 and other pending federal education legislation aimed at assisting states to implement fully the right to education mandate can be viewed in part as a response to federal court action.

On the executive side, the President's concern for providing the handicapped ready access to the legal system and his directive to the Justice Department to take action to protect the rights of retarded person led to Justice Department participation as friend of the court in right to treatment cases and right to education. Most recently, the Civil Rights Division filed suit on behalf of the United States challenging as unconstitutional the practices of an institution for the handicapped in Maryland.

In addition, a number of Health, Education and Welfare agencies are supporting advocacy efforts (including legal advocacy) on behalf of the handicapped without the ambivalence that has characterized administration support of advocacy on behalf of other disadvantaged groups.

The spread of legal action and the legislative and administrative reaction noted above have led some enthusiastic observers to speak of a rights revolution. Whether it is a revolution, remains to be seen. Yet this much is certain, the decisions to date when considered with other major trends such as increased client militancy, increased provider accountability, decentralization of services, and increased community acceptance of handicapped persons, have the potential to bring about substantial changes in all existing and planned programs that serve or are intended to serve the handicapped. Whether the program changes brought about by legal action will actually accrue to the benefit of the handicapped will depend largely on the ability of planners to weigh the programmatic implications of legal action and translate judicial decisions into program advances.

Implications for Future Planning

A careful examination of the direct program implications of the various legal actions is of considerable importance for comprehensive planning. However, perhaps the major future impact of litigation is grounded in the fact that all the decisions and decrees in one way or another accept, promote and give public policy status to two theoretical constructs which have emerged recently to undergird new approaches to service delivery. These constructs, the developmental model of disability and the principle of normalization, have been most widely used in the context of mental retardation and developmental disabilities but are applicable to all disabilities. Jacobus ten Broek set forth similar concepts of integration for blind and other physically handicapped persons, and Richard Allen has given some thought to an across the board legal application of normalization to all handicapped persons. The developmental model of disability views all handicapped persons as capable of growth, learning and development. Human development and behavior are products of interaction between the individual and his environment rather than attributes of a specific impairment. The model emphasizes the potential to alter development and incorporates positive actions to accomplish developmental goals. Consequently, it provides for the accountability of professionals and others for developmental failures brought about by lack of environmental conditions. While the developmental model contemplates intervention to modify both behavior and environment, the normalization principle guides that intervention and requires that the handicapped person have an environment and life-style that is as close to normal as possible. The normalization principle has been translated for use in educational services, residential services, transportation, social services and other human services.

The developmental model and normalization principle provide a sound basis for the development of legal theories to protect rights of deaf-blind and other handicapped persons. The developmental model of disability not only undercuts many of the assumptions behind existing statutes and common law restricting handicapped persons, but it provides a great part of the rationale for judicially mandated affirmative action to modify conditions detrimental to handicapped persons, but it provides a great part of the rationale for judicially mandated affirmative action to modify conditions detrimental to handicapped persons. The normalization principle provides the courts with a useful gauge to develop standards of fairness and due process and assess accountability in relation to the extent to which practices isolate handicapped persons. In this regard, the normalization principle links up with a congruent legal principle of right to least restrictive alternative. Generally stated, it holds that where governmental activity leads to regulation adversely affecting constitutionally protected activities or constitutionally preferred groups, there is an obligation to explore and employ alternatives which can accomplish governmental purposes through means least restrictive to personal liberties. Many lawyers believe that this legal principle can be developed to frame our approach to challenging discrimination against the handicapped in whatever form it may take and in whatever setting it may occur. One may speculate, however, that in this area the law will not venture ahead of practice and that strength of the legal principle of least restrictive alternatives rests largely on the consistent articulation and application of the development model and normalization principle to all services for all handicapped persons, and the actual development of a range of alternatives for handicapped persons. Thus, it is imperative as legal action continues and becomes more complex to consider *in advance* what these legal propositions mean in terms of programs for deaf-blind persons with particular attention to the world of work, sheltered work, economic security, domestic relationships and other important areas of adult functioning.

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1. Burnham v. The Department of Public Health of Georgia, 329 F.Supp. 1335 (N.D. Ga. 1972).
2. Donaldson v. O'Connor, 493 F. 2d. 507 (5th Cir. 1974).
3. In the Interest of G. H., a Child, Civil No. 8930, Supreme Court of North Dakota, __n.W.__(April 30, 1974).
4. Jackson v. Indiana, 406 U.S. 715 (l972).
5. Lebanks v. Spears, 60 F.R.D. 135 (E.D. La. 1973).
6. Maryland Association for Retarded Children v. State of Maryland, Equity No. 100/182/77676 (Circuit Ct. Baltimore Cty. Md., May 3, 1974).
7. Mills v. Board of Education of District of Columbia, 348 F.Supp. 866 (D.D.C. 1972).
8. Pennsylvania Association for Retarded Children V. Commonwealth of Pennsylvania, 334 F.Supp. 1257 (E.D. Pa. 1971) AND 343 F.Supp. 279 (E.D. Pa. 1972).
9. Welsch v. Likins, 373 F.Supp. 487 (D.C. Minn. 1974).
10. Wyatt v. Stickney, 344 F.Supp. 373, 344 F.Supp. 387. (M.D. Ala. 1972).

Information on cases affecting handicapped persons is updated periodically in the following publications:

1. Continuing Summary of Pending and Completed Litigation Regarding Education of Handicapped Children, Council for Exceptional Children, Reston, Virginia.
2. Mental Retardation and the Law, Office of Mental Retardation, Coordinator, Department of Health, Education and Welfare, Washington, D.C.
3. Newsline, National Center for Law and the Handicapped, South Bend, Indiana.

Model Programs

A Time to Think: Future Needs of Deaf-Blind Persons

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The requisite strategy to planning is thinking. This presentation will refer to productive thinking as defined by Guilford (4) as a construct to be used in initial planning. Data will be reviewed which provides a baseline of information currently available. From these data, issues will be raised to serve as a model for the beginning steps of planning, and specific answers will be provided to illustrate some ways in which thinking may lead to new or different solutions to problems. A model of future services has been included to serve as one illustration with the challenge for others to try to generate other models of services for deaf-blind persons in the future.

Productive Thinking

In the factor analysis of the structure of intellect, Guilford (4) described two areas of productive thinking. Divergent thinking utilized a premise from which departures may be made to try to discover all possible alternatives. "*. . . We think in different directions, sometimes searching, sometimes seeking variety.*" (4, p. 16) Divergent thinking in planning for the future of deaf-blind children provides a way to extend beyond our current mental set and methods of operation. It is possible, using a divergent approach, to ask questions which are not currently being considered and to raise issues which will need to be resolved in the near future. Convergent thinking utilized all potential components to synthesize a particular conclusion. "*. . . The information leads to one right answer or to a recognized best conventional answer.*" (4, p. 16) In planning for the future of deaf-blind persons, convergent thinking may be used to draw upon many disciplines (management, medicine, sociology, political theory, etc.) to try to bring together resources which will provide specific answers to problems.

At this time, it is possible to collect the information currently available regarding deaf-blind persons and services to this population and to utilize productive thinking to arrive at specific answers (convergence) or to raise issues which need further inquiry (divergence). The important point seems to be to knowingly utilize these thought processes to thoroughly assess the possibilities of the future needs of deaf-blind individuals.

Review of Factual Data

At the present time, there are 4,096 known deaf-blind persons in the United States between birth and twenty-one years of age. (2) Table I provides the distribution of cases by age for the ten regions, with accompanying data providing current status of services.

Inspection of these data indicates that at the present time there are 3,563 individuals receiving services (eighty-seven percent of the known population). Services, in relation to this distribution, have been categorized as:

1. full-time educational service, day and residential;
2. part-time educational service, day and residential;
3. less than thirty hours a year, diagnostic, evaluation, or home program; and
4. receiving no services, awaiting assessment and placement.

While there are eighty-seven percent of the population receiving services as reported in this distribution, these data do not yield information as to the quality of these services.

Further investigation of these data indicates that by 1980 the range will fall within the categories listed in Table II, excluding estimates for the birth to six years age range. It is important to note that the exclusion of estimates of the early years does not imply that in 1980 there will not be a population of deaf-blind children, birth to six years of age. It is an attempt to maintain the factual base and to highlight the lack of predictive ability currently available to estimate incidence in this age range. It may also serve to indicate that the characteristics of the deaf-blind population will more than likely change by 1980. The rubella vaccine has been effective in disrupting the seven year cycle of epidemics. Therefore, it seems reasonable to assume that there will be another large population of post-rubella

TABLE I
DISTRIBUTION OF KNOWN POPULATION OF DEAF-BLIND PERSONS, BIRTH TO 21 YEARS

AGE	NO SERVICES	IN PROGRAM
0 - 2	11 (.3%)	49 (1.2%)
3 - 5	54 (1.3%)	361 (8.8%)
6 - 8	92 (2.2%)	711 (17.4%)
9 - 11	127 (3.1%)	1,311 (32.0%)
12 - 14	54 (1.3%)	359 (8.8%)
15 - 17	64 (1.5%)	375 (9.2%)
18 - 21	72 (1.8%)	243 (5.9%)
21+	21 (.5%)	102 (2.5%)
Unknown	38 (.9%)	52 (1.3%)
Subtotal	533 (13%)	3,563 (87.0%)
TOTAL	4,096 (100%)	

TABLE II
ESTIMATED DISTRIBUTION OF KNOWN POPULATION OF DEAF-BLIND PERSONS, BIRTH TO 21 YEARS, IN 1980

AGE	NO SERVICES	IN PROGRAM
0 - 2	0 (0%)	0 (0%)
3 - 5	0 (0%)	0 (0%)
6 - 8	11 (.3%)	49 (1.2%)
9 - 11	54 (1.3%)	361 (8.8%)
12 - 14	92 (2.2%)	711 (17.4%)
15 - 17	127 (3.1%)	1,311 (32.0%)
18 - 21	54 (1.3%)	359 (8.8%)
21+	157 (3.8%)	720 (17.6%)
Unknown	38 (.9%)	52 (1.3%)
Subtotal	533 (13%)	3,563 (87.0%)
TOTAL	4,096 (100%)	

Source: Dantona, R., Bureau of Education for the Handicapped, U.S. Office of Education, Washington, D.C., 1974.

children born similar to those born during the 1963-65 epidemic.

Thus, by 1980, the population currently identified as being deaf-blind will center in the age range of 15 to 21 years. This must have a profound effect on our thinking, planning, and implementing services for the deaf-blind.

Other factual information currently available indicates that most services developed during the past five years have been for very young children, such as home centered programs, early childhood education services, family counseling, and primary academic level programs. By 1980, the need for these services will have changed. There is also indicated that many deaf-blind children are residents of state facilities for mentally retarded children. Data is not currently available as to the appropriateness of this type of placement. It may be assumed that some deaf-blind children will need total care throughout their lives, however, efforts to discriminate between those institutionalized children needing total care and those capable of more independent functioning are only now emerging (as in California and Michigan where formal programs are planned to remove children from state-supported hospitals and schools and return them to community-based programs).

It is also a fact that there are facilities which have maintained quality services for deaf-blind persons for many years, such as the Perkins School, the New York Institute for the Blind, Michigan School for the Blind, Washington State School for the Blind, and the Alabama School for Deaf-Blind. These institutions have been affected by the recent increase in emphasis in program development at local and state levels. Reappraisal of their roles in the education of deaf-blind persons has been required. It would seem to be a loss to the field if these quality programs were required to change for the sake of change alone, and the resources which they offer are not fully utilized in future planning.

One last fact seems to be most important. This is the recent development of a cadre of effective persons to work with deaf-blind children. Some of these individuals have received preparation in college and university programs in the area of deaf-blind. Some have been recruited from other areas of education. Some have developed skills through on-the-job training in programs for deaf-blind children. Planning for future services needs to include consideration of the best utilization of these personnel. Most of these individuals have received experiences with very young deaf-blind children. There are very few of these personnel who have worked with adolescent deaf-blind persons or adults who are deaf and blind.

Issues Raised

In a recent planning session with vocational rehabilitation personnel in Arkansas, Louisiana, Oklahoma, and Texas, the question was asked, "What are the service needs of deaf-blind adolescents?" Through a nominal group process, some seventy-six items were listed as potential needs. In voting priorities for the most important needs, the first choice by this group of participants (sixty-eight persons) was "administrative committment" to services. In discussing this priority with participants, it was brought out that the participants felt that they could do almost any of the items listed as top priorities (communication skills, development for vocational training staff, sheltered work settings, long-range case management, early identification of potential clients, etc.) if they had commitment from above to provide this service. What commitment is there to services for deaf-blind persons for the next three, five, fifteen years? Are these committments federally based, state generated, or locally sponsored? What is the process, administratively, for gearing up programs for the future with assurance that these programs will have administrative commitment to provide long-range services?

A second issue is one which has been discussed among the regional center coordinators over the past five years. This is whether the deaf-blind population is unique or whether there is a larger population which would benefit from the types of services currently offered through programs for deaf-blind children. The regional center staff in Denver has referred to this population as "low incidence, high risk." Others have referred to the population as severely handicapped. Is there commonality among populations which would lend itself to similar programming and services, such as current regional center endeavors? Would it be beneficial for programs for deaf-blind persons to be more aligned to a larger population: Will regional centers be encouraged to expand activities into other types of disabilities or multiple disabilities? Will deaf-blind persons become lost among a larger population of multi-impaired in regard to services? Will services and funding be diluted by this expanded concept?

As the majority of the population grows older, what is to be done with the early childhood education and infant stimulation programs which have been developed for deaf-blind children? Should specific programs begin to merge so that there are fewer such programs? Should staff be retrained to work with older youth and adults? Will states be encouraged to pick up funding on these early childhood programs for use with other populations?

How will all services to deaf-blind persons in this country be coordinated? Will regional centers be able to identify and serve specific problem populations, such as the Usher syndrome cases when a person is congenitally deaf and begins to lose vision during adolescent years? What is the relationship of regional centers to state rehabilitation agencies, federal vocational rehabilitation programs, the National Center for Deaf-Blind Youths and Adults, the social security amendments?

What is the role of the regional center in the future? Will the regional centers be phased out of federal funding? Will the number of regional centers be reduced with specific centers providing unique services on a national basis? What transition is required to reduce the regional center's role in direct services and to increase other activities, such as regional resource centers, consultation to programs, evaluation of program services or diagnostic services to deaf-blind persons? Will states be able to pick up services to this low incidence population?

Are skills available to research what is being done *for* deaf-blind children? Specifically, can the quality of services which are emerging be evaluated? Perhaps even more to the heart of the matter is the question: What are programs doing *to* deaf-blind children? Where do program services lead? Recently, a fourteen year old deaf-blind boy was withdrawn from a day school program in his home community by his parent and enrolled in a state school for mentally retarded children. The young man had grown to where the parent felt that she could neither manage his behavior nor accept further responsibility for him. In frustration, the teacher stated that if she had known that this would have been what was going to happen to the student, she would have spent more time trying to teach him to occupy himself with light play or rocking and learning not to bother others instead of teaching him communication skills and academic readiness. If the cynicism of this remark may be held constant, it does seem to raise an issue: Is what we are doing now going to help deaf-blind individuals have a "better" future? What is the qualitative goal for deaf-blind education? Can we predict? What skills are needed to reach prediction? How long will it take to arrive at this level of research?

What other issues may be raised? What forum will be available to continue to raise issues? Perhaps it is at this point that the reader would take time to list possible alternatives which need consideration regarding these issues.

Specific Answers

It seems evident that the next six years, until 1980, emphasis will be placed upon two areas of programming: services to adolescents and their families, and services to children and youth not currently in appropriate placements. This may mean that a new type of personnel will be needed. One possible type would be a case manager. This person would be assigned to a caseload of several deaf-blind persons and would have the responsibility of developing individual programs, finding resources to meet each client's needs, assuring that delivery of services is appropriate, and serving in various capacities to facilitate services by others to deaf-blind persons. This person may serve as an advocate for services, a coordinator to utilize all existing resources, a manager to outline resource and progam needs, and a steady contact for client and family. This person might be employed by a regional center and assigned to a state or local agency, or even work out of his/her home. This person might be similar to the itinerant teachers being used in some programs to provide outreach services. It would be important that this person have access to many agencies and resources. It may even be that this person would need to function in a role which Barshop (1) defined as triage:

> *Triage refers to a system of assigning priorities. In the medical and military professions, it has meant the assignment of priorities of medical treatment to battlefield casualties on the basis of chance for survival, urgency, and so on. The French have the phrases gare de triage, manoeuvres de triage, and triage a la main for marshalling, shunting, sorting, and handpicking operations. Implied in triage is rapid incisive decision making in the setting of priorities such that very costly time or resource loss does not occur. (p. 104)*

Within the next six years, it seems that there will be a definite need for the development of supervised, locally based living/training/working programs for deaf-blind youth and adults. These may be patterned after some of the halfway houses currently used in vocational rehabilitation with an extension of services for the lifetime of the client. These may be variations on the respite care centers which are being considered in local communities for families of impaired children, where the deaf-blind youth or adult lives in the center for periods of time and returns to family or community living arrangements for periods of time.

In the near future there will be a definite need to evaluate the efforts of the regional centers. Criteria must be developed for such undertakings which make allowance for the unique structure and role of each center, as well as objectively reviewing the efforts of all centers as they relate to the quality of services to children and youth.

It would seem that this evaluation would need to be coordinated on a national level and that it would require sophisticated research methodologies to assure appropriateness of data collection and analysis. One of the points which Guilford made in discussing productive thinking was that it would be commendable to be able to come up with ten possible solutions to a problem, but evaluation is necessary to decide which is the best solution. (4, p.21) Evaluative thinking is also an important aspect of the structure of intellect, and in program planning, evaluation is essential as a primary component.

From all the suggestions made regarding programs and services needed for deaf-blind persons, it may be possible to list more specific answers which will enhance these services.

One Model of Service

From the use of raising issues and providing specific answers to some problems which are projected for the future of deaf-blind persons, one model of services may be offered to illustrate approaches to services. This model is not offered as an ultimate product, but as a springboard for the generation of future approaches to the delivery of services to deaf-blind persons. Other approaches are needed. Figure 1 provides one model. The challenge is that efforts be made to present graphically other models of services.

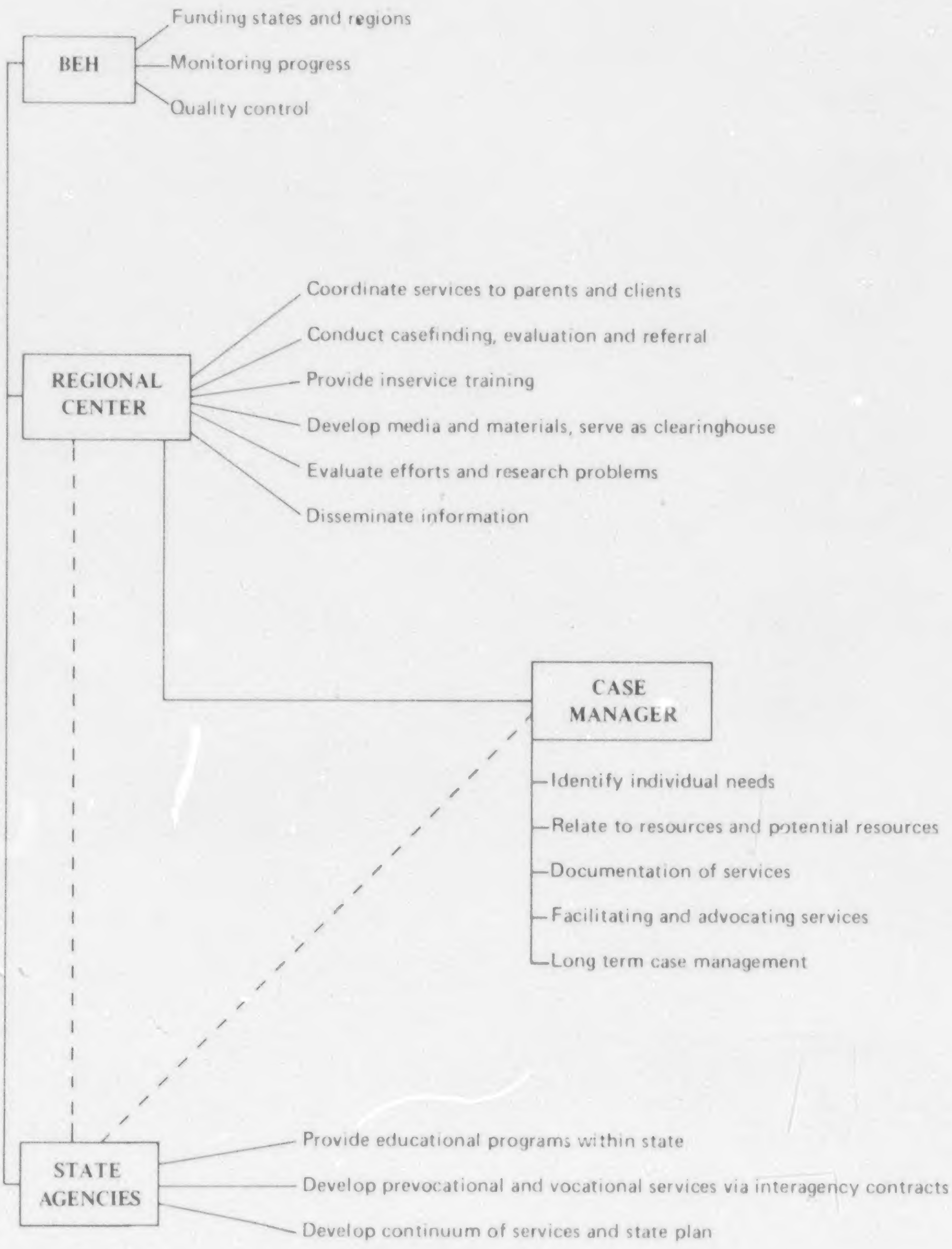
Summary and Conclusions

Planning for future services requires time to think in a wide range of ways about all the problems and possible solutions which will be encountered. There are data which indicate the configuration of part of the population for the next few years. There are specific statements which may be made from inspection of these data. A partial list of issues which will be faced in the near future has been offered to encourage the further listing of issues and problems. Some specific answers have been detailed to challenge further efforts to provide a range of solutions. One model has been graphically presented, without written interpretation, with the request that other models be identified so that a full configuration of the methods of delivery of services to deaf-blind persons may be thoroughly explored.

English (3) reviewed rehabilitation services for deaf-blind persons and illustrated the need for planning. In concluding this paper, it was stated:

FIGURE I

ONE MODEL OF SERVICE FOR 1980


BEH
Funding states and regions
Monitoring progress
Quality control
REGIONAL CENTER
Coordinate services to parents and clients
Conduct casefinding, evaluation and referral
Provide inservice training
Develop media and materials, serve as clearinghouse
Evaluate efforts and research problems
Disseminate information
CASE MANAGER
Identify individual needs
Relate to resources and potential resources
Documentation of services
Facilitating and advocating services
Long term case management
STATE AGENCIES
Provide educational programs within state
Develop prevocational and vocational services via interagency contracts
Develop continuum of services and state plan

Time seems to be the critical factor. Unless planning and coordination is begun immediately, vocational services, the capstone of the continuum of services needed by deaf-blind persons, will not be available to the number of deaf and blind adults needing these services. (p. 12)

The statement that 1980 is now will be repeated many times during this conference. However, there is time to think through these problems, to plan for future services, and to implement these so that quality services are available to deaf-blind persons in the future.

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1. Barshop, Kathleen H. The Functions of Regional Social Work: A Case Study. Unpublished Master's Thesis, Graduate School of Social Work, The University of Texas at Arlington, 1973.
2. Dantona, Robert. Personal Communication, April 1974.
3. English, Jack. Rehabilitation Services of Deaf-Blind Individuals: Need for Planning. Dallas: Callier Hearing and Speech Center, 1972.
4. Guilford, J.P. Three Faces of Intellect: Intelligence, Creativity, and Their Educational Implications. San Diego: Robert R. Knapp, 1968, 14-32.

Policy Statement from the Bureau of Education for the Handicapped

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Although the Constitution leaves education to the states, the federal government has traditionally accepted responsibility for underwriting programs that are not cost-effective on a state level, and for providing supplemental support to equalize educational opportunities in the nation at large. Curriculum research and development, bi-lingual and vocational programs, and most of what the Office of Education still does is directed toward meeting these needs. Education for the handicapped is particularly important in this context because it is more specialized and therefore less cost-beneficial to develop on a state level, and because it is needed most by economically disadvantaged children, who tend to be disproportionately handicapped and unable to "follow" new programs to other cities and states.

There are approximately seven million handicapped children in the United States who need special education in various degrees. And since 1971, the Office of Education has agreed that they have the same right to an education as other children, and that society has the same need to guarantee that right. But even with the increase in federal support for new programs, less than half of them are getting the kind of education that could make them maximally self-supporting.

The Problem

Existing state programs for special education are inadequate. Although forty states now have mandatory special education laws, no state is currently serving its entire population of handicapped children. Areas in greatest need of support are:

1. Identification of children, particularly economically disadvantaged and minority children.
2. Diagnostic placement and evaluation.
3. Program coordination of childrens' total needs.
4. Mainstreaming of those children who could benefit from inclusion in the regular education system.
5. Development of quantifiable measures of existing programs.
6. Adequate training of special education teachers.
7. Adequate training of regular education teachers who could assume greater responsibility for teaching handicapped children in their classrooms.

Proposed Solution

Increasing federal support for identification, prevention and pre-school education, diagnostic and placement services, deinstitutionalization, programming for low incidence and geographically isolated children, and vocational training and job placement for handicapped youth and adults, including:

1. Establishment of such minimal conditions for federal support as state acknowledgement of responsibility for providing special education services to all children who need them.
2. Development of multidisciplinary diagnostic teams to identify at the earliest age possible those children who need special education.
3. Revision of higher education teacher-training curricula to prepare regular teachers to recognize and be of assistance to handicapped children who may be in their classrooms.
4. Subsidizing of special programs to retrain regular teachers who may want to work with handicapped children.
5. Organizing and assisting cooperative efforts between school districts to take advantage of the economics of scale in educating low-incidence handicapped children.
6. Working with state agencies to develop guidelines for quality educational programming in both residential and special day institutions.
7. Working with state agencies and prospective employers to develop vocational programs that will lead to real jobs.

Triple Team Approach

Edgar L. Lowell
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If you have ever been annoyed or frustrated because a research or demonstration project which sounded as though it might be of some interest or value to you was *not* because it was poorly executed, improperly evaluated or inadequately documented, the Triple Team approach may provide a solution. Triple Teaming is a suggested approach to funding model or demonstration programs. This approach would insure model programs that their underlying concepts would be fairly demonstrated, appropriately evaluated and thoroughly documented.

Model programs are frequently supported with the assumption that their unique or improved methods for the delivery of service or their service related activity will be replicable in other locations. The Triple Team approach grew out of the realization that there are a number and variety of constraints preventing the successful replication of model programs.

Evaluation

Before a program is replicated, it must be evaluated and documented. You want to know how good it is and whether or not it will fit your needs and your budget. Adequate and objective measuring instruments are rarely available. Evaluation systems in the behaviorial sciences are limited, particularly in such a specialized field as the deaf-blind. As a consequence, evaluation tends to fall into one of the following types:

1. *Standardized Test Approach.* The applicant reports that evaluation will be performed, utilizing a comprehensive list of standardized tests, most of which are inappropriate for the subjects or the objectives of the project.
2. *Behaviorial Objectives Approach.* This has the most promise, but for a variety of reasons is frequently weakened either by specifying trivial objectives, or by reasonable objectives which are not evaluated until the completion of the project and thus perform no guidance role.
3. *To Be Developed.* The project director and staff will develop evaluation instruments during in-service training sessions or in two weeks before the project starts. They generally indicate that these instruments will cover many areas of human behavior. These proposals are perhaps the weakest because they suggest that the proposers are not sufficiently aware of the magnitude of the problem.
4. *Farmed Out.* Generally a specialist from a nearby college or university will be retained on a part-time basis to do the evaluation. Somehow, he is supposed to insure appropriate evaluation. This is not to suggest that there are not well qualified evaluation specialists but only to point out that personal expertise should be used in addition to rather than in lieu of valid measuring instruments.

Dissemination

After the project is evaluated, the results must not only be disseminated, but documented. This is likely to consist of:

1. Opportunities for people to visit and observe the project.
2. Papers or workshops given by project personnel at professional meetings.
3. At some delayed period of time after the completion of the project, a final report.

Each of these helps to inform others of the existence of the project, but they are not particularly helpful to someone who wants to replicate the program. Videotape has been used in some of these dissemination efforts, but it is generally in the "show and tell" tradition, presenting examples of the best of the staff working with the best of the participants under ideal conditions.

Replication

If replication rather than publicity was the goal, it would be desirable to focus our efforts on a thoroughly documented "how-to-do-it" manual. This manual would cover the activities of the project from its very beginning. What were the decision points? What was the rationale for decision making? What mistakes were made, as well as what successes? What kinds of activities went on as a part of the project? What were the skills required of the staff? This manual would provide enough information about skills, procedures and materials to realistically portray to the interested agency everything that would be involved in attempting a replication of the project and would give them specific help in getting started.

Funding

Funding with the Triple Team approach would, in the long run, be the most economical. No one wants to submit a proposal that will be turned down because of cost. But efforts to reduce the budget generally show up in the areas of evaluation, documentation and dissemination. They are mentioned in the application only because the guidelines call for them. This paper suggests that funding through the Triple Team approach would allow demonstration projects to be set up that would provide adequate service, thorough evaluation, and rapid dissemination.

Under the Triple Team approach, demonstration projects would be staffed by three separate teams. One team would provide the service, another the evaluation, and the third documentation and dissemination. This does not mean that there would be three staffs of equal size. This imbalance between service, evaluation and documentation might be solved by the addition of as few as one or two staff members. The emphasis would be on funding and staffing the projected model program according to sound psychological and educational principles, rather than budgetary constraints.

For example, this might mean an increase in the educational staff serving deaf-blind children in a residential institution. In some of these situations, the education staff works with the children five hours a day and then turns them over to ward personnel who, for a variety of reasons, may have little or no knowledge concerning the objectives of the educational program and little training or skill to permit them to reinforce and implement the educational program during the balance of the child's day. Under the Triple Team approach, the service staff would be augmented with residential staff personnel qualified to carry on reinforcement of the educational program during the child's out-of-school hours. This is a limited example. In many projects there are situations in which budgetary or other constraints interfere with the operation of an ideal program. Under the Triple Team approach, the service component would be optimized in the belief that a small addition to the staff might produce significant improvements.

The evaluation team would have a primary responsibility for developing and carrying out an evaluation of the program. This would be an ongoing program with feedback to the service staff so that activities and objectives could be modified in the light of experience. This team would be staffed with whatever personnel might be required to carry out a comprehensive and meaningful evaluation. The composition would vary with the nature of the project. An adequately staffed evaluation team might develop and validate badly needed measuring instruments.

The documentation team's task would be to provide an ongoing and complete documentation of the project with particular emphasis on detailed descriptions of typical activities and a careful analysis of the skills utilized by the staff in carrying out the program. Hopefully, such a skill analysis might lead to the definition of a training program for personnel to staff such programs, if widespread emulation was indicated. One objective of the documentation team would be to have their descriptive report completed as soon as possible after the termination of the project. The written report would be augmented with whatever media might be appropriate to make their completed package the most useful to others wishing to replicate the program. The documentation team would be judged successful if their report:

1. permitted other interested parties to understand enough about all aspects of the program so that they could make informed judgments about the feasibility and potential value of attempting to replicate the service in another location.
2. was complete enough to provide significant assistance to those attempting to replicate it.
3. was completed shortly after termination of the service component.

Admittedly the costs of these Triple Team projects would be more expensive than a more typical demonstration program. The increased value of adequate evaluation and documentation, as well as the possibility of immediate replication of the project, would outweigh the extra costs. This approach seems particularly appropriate in the field of the deaf-blind where the numbers are small and the array of demonstration projects is potentially smaller. If the dollar support of demonstration projects was kept constant, this might lead to a more careful selection of projects to be supported, which would more accurately reflect priority needs.

Project Monitor

A potential problem relates to the interaction of the three teams. The likelihood of serious differences of opinion should be recognized. Each team would presumably have different interests and, hopefully, considerable ego involvement in their own efforts. It would seem undesirable to place the overall project direction under the head of any of the three teams, because of the potential that one point of view might dominate the project.

To avoid this possibility it is suggested that a project monitor, selected by representatives from each team, be employed to oversee the project. The project monitor would meet with the teams for regular progress reports. It would be his responsibility to serve as referee in differences of opinion and his obligation to report failures to meet objectives to the sponsoring agency. Ideally, the project monitor, while committed to the success of the project himself, would be independent of the team members—perhaps even associated with another institution.

Advantages

Demonstration projects which offer the promise of meeting the emerging needs of our target population should be funded utilizing the Triple Team approach. Triple Teaming means that model programs of interest and value will be fairly demonstrated, appropriately evaluated and thoroughly documented. Triple Teaming means that needed programs will be available for immediate replication. To insure continuing progress and development of deaf-blind children in 1980, the Triple Team approach is needed now.

Alternatives to Hospitalizing Developmentally Handicapped Children for Care, Treatment and Education: Part I

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Experimental Training Program

The Importance of Adequate Parenting

A considerable body of knowledge has accumulated over the past four decades about the importance of adequate parenting of children to become mentally healthy, happy, and productive adults. Spitz (10, 11) reported in a series of papers on the devastating effect which deprivation of adequate parenting has on young infants and children. In careful observation of infants reared in a foundling home, he found that the development quotient of infants dropped almost in half during the first year of life and half of that at the end of the second year. These infants became, besides, very susceptible to illness and showed a high degree of mortality rate. He called this condition "hospitalism." At about two years of life, the survivors could not eat alone or move about, were not trained for cleanliness, and had not developed speech or, at the most, learned to speak a few words only. Spitz reported on a control group of children who were born in a penal institution to delinquent girls. The infants of these girls were alert, active, agile, and developed normally. He saw the difference in the outcome of the development of these two sets of children in the different pattern of mothering. The children who were in prison received good care and attention from their mothers who took pride and pleasure in their offspring. On the other hand, the children in the foundling home, although taken care of physically and nutritionally, had only one-eighth of a mother to meet their emotional needs.

Bettelheim and Sylvester (3) speak of psychological institutionalism when no parenting figures are available for a meaningful and continuous relationship with children who live in an institutional setting for a prolonged period of time. It also occurs in children who live in disorganized family settings, or who are exposed to a succession of foster homes. They indicate that no psychotherapeutic measures can be effective if no meaningful interpersonal relationship between adult and child exists when a child is under treatment. Depersonalized rules and regulations in an institution may lead the child to become an automaton in his passive adjustment to an institution, but usually do not lead to an internalization of behavioral controls. In *Truants From Life,* Bettelheim (2) discusses the consequences of deprivation in a case of institutionalism. Bowlby (4, 5, 6) has written extensively on the importance of a child's development of a stable and continuous relationship with a parent or parenting figures. Winnicott (12, 13) reports on the difficulty of treating children who were deprived of adequate parenting and discusses the importance of a "good enough environment," meaning a reliable, continuous, affectionate relationship with the child's parents. The Robertsons (7, 8) reported on the traumatic effect of hospitalizing a child even for a brief period. In a recently published essay, Spitz (11) makes a distinction between learning, which he considers input, and storage of information in the memory bank and fundamental education, which is the process which leads to changes in the child's thinking and behavior through identification with a parent or parenting figure. He points out that some of the failures which were experienced in trying to provide early intellectual stimulation which were attempted with young, deprived children to accelerate their learning process by explaining that these children lacked a fundamental education in the environment in which they were brought up. According to Spitz, the process of learning must be preceded by a process of how to learn, which is part of the fundamental education through identification with a parent or parenting figure.

My own experiences in working with disturbed children in a state hospital over more than two decades led to the conclusion that a state mental hospital, or any institution for that matter, is not the proper milieu for treatment of severely disturbed children. A child is sent to a state hospital for treatment for a variety of behavioral manifestations. The common denominator in all these manifestations is the fact that the control system is out of whack; i.e., the ego system is deficient in some or most of its executive functions. The child is sent to the hospital in the expectation that he or she will find a therapeutic milieu, a concept which was introduced in the literature by Bettelheim and Sylvester (3). Therapeutic milieu is defined as the total management of an environment for the treatment of a child. In the context of his presentation, Winnicott's concept of "the good enough environment" is preferred because the central point of this concept is the parent-child relationship so essential to the growing and developing child, and no less important to the child under treatment. No child under treatment may be deprived of a reliable and affectionate relationship with a parenting figure. Unfortunately, such a reliable, constant, and continuous relationship with a parenting figure is very difficult to come by in a state mental hospital.

Basic Needs

In the most general and simple terms, a child needs three basic experiences to develop into a happy and productive adult. He needs, above all, the experience of living in intimate conditions within a family unit so that he can learn how to relate affectionately and intimately with members of his own family, and with other people when he becomes an adult. He needs the experience of living in a normal neighborhood where he can find out what the world outside of his home looks like. He needs to learn how to get along with his peers, how to play with them, how to compete with them, and how to assert himself; and, finally, he needs the civilizing experience of a public school. Of these three basic experiences, we have been successful only in providing our children with an educational system as good or better than anything that is available to the children in the communities from where they are sent to the hospital. We have not been able, however, to provide the children with experience of how to relate intimately with adults and peers. The reason why we have been successful in the one and not in the other goes to the very heart of treating severely disturbed children. Partly, it is because of factors inherent in the child; and, in part, it is because of the institutional conditions in a state mental hospital.

All, or nearly all, the children who come to a state hospital have one handicap which is common to all of them: the inability or great difficulty of relating to peers and adults. These children find themselves in a dilemma similar to schizophrenic adults which Bellak (1) described through the use of the metaphor of two porcupines wanting to get warmth from each other. If they come to close, it becomes very painful; and if they don't get close enough, they don't get the warmth which they need. Our emotionally disturbed children are skillful in avoiding getting involved in any close relationship with either adults or peers. They would go to any length to thwart any adult who is trying to develop an intimate relationship with them. As a result, a sort of coexistence develops on an impersonal level. The child learns, after awhile, to follow certain rules of conduct under hospital conditions; but there is no personal involvement with staff or attachment which is essential for a growing child for identification and for establishing inner controls. A frequent experience has been that when a child leaves a hospital after a year, or two or three, and returns to his family or is placed in a foster home, he still is incapable of forming relationships and, sooner or later, is returned to the hospital for another period of treatment.

The hospital is a place where staff are trained to focus their attitude on psychopathology. Often the child is looked upon as an appendix, as it were, to his brain damage, his autism, his schizophrenia, or whatever the psychopathology may be. The very fact that he is a patient in a hospital removes him from the category of being a child like other children. He is surrounded by compassion, by protection and forbearance. He is dressed, fed, scrubbed, in the best Hippocratic tradition. But one wonders what such an attitude and expectation does to the self-image and self-esteem of a growing and developing child. Then, there is the factor of changing shifts three times a day, twice a week. The person who puts the child to bed in the evening will not be the same who awakens him in the morning; and chances are that that person will not be the same the next morning, and the morning after next. The few minutes of tucking a child to bed and getting him out in the morning are more important to the child's emotional development than any daytime activity because it makes him more acceptable to intimacies and facilitates the formation of relationships. And this time is lost, both to child and to the staff, of reaching out and developing a reciprocal relationship. The coming and going of people three times a day and changing of shifts twice weekly can only induce confusion in the developing child. One wonders what this might do to his self-image and to his developing capacity for trust in other people and his capacity for indentification. It is through identification with a parenting figure that the child learns how to learn—a process to which Spitz (11) refers as fundamental education—in contrast to the process of learning which consists of input and storage of information in the memory bank. Another factor in this is the ratio of staff to children which would permit intimate and warm relationships between children and staff. On the cottage with our most regressed and severely disturbed children, we usually have staffing to provide, during the waking hours, roughly a ratio of one nursing staff to five children, or eight staff members for forty children. For these eight staff to be actually present during all waking hours, one has to assign actually twelve staff per eight-hour shift during the waking hours, which is enormously costly. It must also be kept in mind that of the eight staff who are expected to be present for the forty children, usually five to six are available at one time. The reason is the high absenteeism because of the strain and stress of caring for these mentally disordered children. But assuming that eight people are available at all times, and there is a ratio of one staff to five children, no intimate relationship can develop in the cottage. Most of the time one would observe disorganization among the children, or random hyperactivity or withdrawal. This is in stark contrast to what happens in our educational setting where a ratio of one teacher to five children produces a very effective educational and socializing experience for the child, which eventually will lead to greater emotional stability. There are several reasons why this ratio is so effective in a school setting and not so effective in a cottage setting. To begin with, in the school we have professionals, with an orientation towards children, who have been trained in the management and education of children in the classroom. Secondly, teachers are not expected to become intimate with children, to take them on their laps and play with them. The relationship between child and teacher is different from that of a child and a parenting figure. The most important aspect is that there is a buffer between the teacher and the child. The teacher is task oriented, and so is the child in a school setting. It is the intellectual performance and the teacher's professional skill which creates a satisfactory, acceptable distance between child and teacher and which makes the experience bearable for both partners. Finally, there is the structure of the classroom which is so very important for the child because it helps him in keeping himself organized. It is a prop to his ego. Limits are set to his movements and his activities. He is kept in place for a predictable time, and the child has to focus his attention on the subject and the teacher. There is a constant flow of ego support from the teacher to the child, providing the teacher has sensitivity and understanding of what is going on between the two in the classroom, and providing the teacher-patient ratio does not exceed one to five at any given time. I referred to this phenomenon on another occasion as "ego transfusion" which helps the fragile ego of a child to maintain some equilibrium in his inner life and in his conduct in the classroom. One cannot but be impressed when one observes the behavior of these very disturbed children in a classroom conducted by a sensitive and warm teacher. The children give the impression to the unbiased observer that they behave like any normal child in a normal school setting. In contrast to this picture, when visiting a cottage after school hours, one is amazed how "crazy" the children look and behave. They either withdraw into a corner or stretch out anywhere on the floor, or throw temper tantrums, throw pieces of furniture around, and are hyperactive in a variety of ways.

Satellite Homes

The comparison of the behavior of the children in a classroom with that in the cottage led to the question, "Why not have the best of two worlds?" "Why not develop a similar educational system in the community where the child lives and provide him with family-like living conditions, if not in his own family, in homes with specially trained figures who could fulfill the family role and provide care and treatment for four psychotic children in such a home?" This reasoning led to the birth of the Satellite Home concept. The crucial point in this scheme was to find out whether it would be possible for professionally trained parenting figures to care for four psychotic children twenty-four hours a day, seven days a week, over a period of several years. If it were possible to develop such Satellite Homes in sufficient numbers to provide for the care and treatment of children who need hospitalization, the long-term treatment of these children would be far more effective, and far less costly, than in a state mental hospital. Much of the cost in a state hospital is benefitting the children only indirectly. To run a hospital efficiently, one needs not only three shifts daily and two overlapping shifts weekly, but one needs, also, several levels of supervision, with several levels of directors, superintendents, business managers, and maintenance personnel, and a very costly hospital structure. By contrast, the Satellite Home requires only the payment for the people directly involved with the children, plus twice-weekly consultation services for the parenting figures, and any decent family home in a good neighborhood which could be had for about $100 a bed per month, instead of a capital investment of nearly $50,000 per bed for building a hospital. The establishment of such Satellite Treatment Homes in the community could provide twenty-four hour care and treatment for children who require such services. Such homes would enable county mental health centers to offer fully-integrated mental health services to children and families who could benefit from them, which would include child guidance, day treatment, and twenty-four hour care.

Staff

To staff such Satellite Homes, we will need to train college graduates to develop skills in the child mental health field, to become professionally trained surrogate parents in such Satellite Homes, and, also, to develop competency in the care, treatment and education of such disturbed children in day treatment centers, in special classes in public schools, and wherever their services may be needed, including nonprofit, twenty-four hour treatment centers for children in the community. Such a training program now exists at the Children's Treatment Center of the Camarillo State Hospital which I started in 1970. The training is now conducted on three levels: the A.A., B.A., and M.A. Each level has a two-year training program, supervised for the A.A. level by the nearby Moorpark College, a community college, and for the B.A. and M.A. levels by the California Lutheran College. Graduates of the M.A. level receive a Master's degree and certificate of competency in child care, and credentials in special and general elementary education for public schools. The training and teaching is done on the campus of the Children's Treatment Center by members of an interdisciplinary clinical staff. Currently, there are about sixty students in training on all three levels. So far, we have graduated two classes—one on the M.A. level, and the other on the A.A. level. We expect to graduate another class on the M.A. level this coming summer.

Operation

We have had four Satellite Homes in operation for the past four years. Two such Satellite Homes were established on the hospital grounds, several blocks away from the hospital, in the employees' village where physicians and their families and administrative personnel live like in any other normal neighborhood. A number of families have young children and live in single homes, and family living conditions and the neighborhood are comparable to any neighborhood in a community. A home in such a neighborhood seemed to offer, therefore, community-like conditions for establishing an experimental Sattelite Home where we could observe the operation of the home under family-like conditions and compare the behavior of the children treated in such a home with that of the children in the nearby hospital. We could compare the effect on the treatment of the children of a stable and continuous relationship which these children developed with the parenting figures in the Satellite Home with the lack of such stable and continuous relationship with the staff who functioned as parenting figures with the children who were treated in the hospital. We have since also developed two Satellite Homes in the community—one in Camarillo and another in the San Fernando Valley. The Satellite Home in Camarillo has been in operation for about four years, the one in San Fernando Valley close to a year and a half or so.

Results

Our observation of the behavior of the children in the Satellite Homes on the hospital grounds, in many respects, confirmed a number of our expectations which we had about children treated in such homes:

1. First of all, after a brief period of adjustment to the new conditions, the children intermingled with the neighborhood children of the other employees and behaved, to all appearances like these children. During their free time, they played on the front lawns of their homes or the homes of the other children. They played with them, they ran with them, and they moved freely without the need for continuous supervision. Over a period of nearly four years, in four different Satellite Homes, we had no runaway episodes. This is in contrast to frequent occurrences of runaways at the Children's Treatment Center. It is in contrast to the need for constant watching of their movements and to keep them behind a chain-link fence while they are being treated at the hospital.
2. Close attachments were formed between children and parenting figures to such a degree that when children left after six months or two years to be returned to their own homes or to traditional foster homes, the loss was perceived and felt by the surrogate parents as if they had separated from their own children and required weeks of preparation for such an event; and the same applied to the children.
3. On theoretical grounds, and on the basis of our clinical experience, the Satellite Homes in the communities could be used as effectively for the care, treatment, and education of retarded, deaf and blind children as they have been used for the care and treatment of severely mentally disordered children. The curriculum for training of Child Mental Health Specialists could be somewhat modified to prepare them to function as surrogate parents for deaf and blind children by having them trained in specific techniques which would be applicable for such children. The setting up of Satellite Homes in the community, in combination with special education and day treatment centers for deaf-blind children, could be made an integral part of any educational or treatment system in each community where such handicapped children live without investing large sums of the taxpayers' money in building and operating institutions.

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1. Bellak, Leopold. Schizophrenia, A Review of the Syndrome. Logos Press, New York. 1948.
2. Bettelheim, Bruno. Truants From Life. The Free Press, Glencoe, Illinois. 1955.
3. Bettelheim, B., and Sylvester, E. The Therapeutic Milieu. American Journal of Orthopsychiatry. 18:191, 1948.
4. Bowlby, John. Maternal Care and Mental Health. Geneva: WHO, New York University Press. 1951.
5. Bowlby, John. Attachment and Loss, Vol. I. Basic Books, Inc., New York. 1969.
6. Bowlby, John. Attachment and Loss, Vol. II. Basic Books, Inc., New York. 1973.
7. Robertson, J., and Robertson, J. Film Series, Young Children in Brief Separation. New York University Film Library. 1967-73.
8. Robertson, J., and Robertson, J. Young Children in Brief Separation: A Fresh Look. Psychoanal. Study Child. 26: 264-315. 1971.
9. Spitz, R. A. Hospitalism. The Psychoanalytic Study of the Child. Vol I, International Univ. Press, New York. 1945.
10. Spitz, R. A. "Hospitalism, A Follow-up Report." The Psychoanalytic Study of the Child. Vol. II. International Univ. Press, New York. 1946.
11. Spitz, R. A. In Maria W. Piers, (ed.) Fundamental Education, Play and Development. W. W. Norton & Company, Inc., New York. 1973.
12. Winnicott, D. W. The Antisocial Tendency. Collected Papers. Basic Books, New York. 1958.
13. Winnicott, D. W. The Maturational Process and the Facilitating Environment: Studies in the Theory of Emotional Development. International Univ. Press, Inc., New York. 1965.

Alternatives to Hospitalizing Developmentally Handicapped Children for Care, Treatment and Education: Part II

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If one could make a general statement about the planning for the care, treatment and education of mentally handicapped children which could also apply to other developmentally handicapped youngsters such as the deaf and blind, it could be best summarized under four headings:

1. The Physical Environment
2. The Human Environment
3. The Emotional Support System
4. Prevention

The Physical Environment

The physical environment has a number of other facets than those mentioned under the Satellite Treatment Home concept. For instance, the physical environment may refer, as in the case of the Satellite Home, to the broader surroundings of a normal neighborhood in the community. Or, it may refer to the more immediate and limited concept of space by which the child is surrounded in a hospital setting, meaning the size of the room, the quality of the space in which he lives, such as the colors of the wall, the light, the cheerfulness of the total view of space within a room.

The impact of the physical environment on emotionally disturbed children and how it affects the well-being of patients in a state hospital has received little attention in the past, either by administrative psychiatrists or by architects who build the hospitals. The well-being of the normal human being, his effective functioning in whatever capacity, his productivity, is greatly influenced by the way he uses the physical space in which he spends his time. This often escapes notice by the person who has a small area to deal with, such as his own home. But it looms large to an administrator in charge of substantial physical areas housing mentally ill children. Perhaps it is also because of our excessive familiarity with the problem of space that its psychological significance has received a minimum of scientific study, particularly in regard to its effect on mentally ill children. Physical space owes its significance largely to the critical role it plays in the interpersonal affairs of everyday life. It determines who associates with whom and under what general conditions. The freedom of choice open to the individual is usually maximal in the selection of dwelling space, more restricted in the selection of where to work, and is one of the aspects of everyday life most readily sacrificed by the mentally ill patient who must seek the resources of a state hospital. When it comes to providing proper housing for children in a state hospital, the quality and distribution of space may have a modifying influence on their behavior. For psychotic children, because of their poor ego boundaries and distorted perception and difficulty in orientation in time and space, a properly structured environment is of paramount importance.

The physical environment includes not only the number of square feet per patient, which has become the sole preoccupation of state hospital planners and administrators, but, far more important, includes the quality of space. How one uses space, the color of the walls, the style and color of furnishings one puts into it, how one adapts space to the needs of different children, is far more important than the number of square feet which are apportioned to each child in a cottage. The impact of the physical environment on the well-being and on the behavior of the mentally ill child is far greater than we have been led to believe by the casual and scant attention which this has received by hospital planners and hospital administrators in the past. I consider it to be an important factor which influences the child's behavior during his residence in such a facility—it is ubiquitous; and, therefore, it affects the child's behavior twenty-four hours a day; and it is the least costly tool of ego support in such a residential setting. One can gauge the impact of the environment on the patients by observing the adult mentally ill patients' behavior on a hospital ward where they spend their time, day in and day out, in reclining, heavy, steel-framed chairs, strung along the wall. Such a chair forces the patient into passivity and dependency, and the arrangement of the chairs encourages emotional and social isolation. Similar space arrangement had been attempted sixteen years ago when our new children's facility had just been completed. The identical chairs were strung along the walls in the same arrangement, but with different results. Fortunately, or unfortunately, depending on one's viewpoint, children have a way of letting their displeasure and discomfort be known to their environment through their behavior. We had a period of massive destruction on all our cottages with hundreds of window panes broken every month. This period has left an unforgettable impact on my mind and led to the development of the concept that physical space and all aspects of its arrangements, including color of the walls, the shape of the furniture, etc., has a behavior-modifying influence on our emotionally disturbed children, and particularly on the psychotic child. It led to the theoretical concept that we not only carry within us as a part of our psychological makeup, our body image but the space surrounding the body image as well, which may explain, perhaps, the discomfort which all of us feel when returning home from a hard day's work, we find some furniture completely rearranged. If normal adult people lose their emotional equilibrium by such a rearrangement of the furniture, how much more will it affect the young schizophrenic child who has difficulty with his body boundaries, his orientation in space, changing muscle form in the maintenance of posture and equilibrium, because of immature postural and righting reflexes so b[illegible] for man's orientation in his environment. With this in [illegible] we designed special furniture to take into account the [illegible]dicaps of the schizophrenic children; and with the financial help from outside sources, we had it custom made and refurnished our cottages. In the cottages for the schizophrenic youngsters, the furniture is bolted down on a platform attached to the floor. When the child wants to sit at a table, he has to squeeze himself into a chair, and in doing so becomes aware of his separateness from his environment—of his body boundaries. The chairs have straight backs, and his posture is such that he is alert and in a prepared posture to perform. On the other hand, when time comes to move around freely, the space is so structured that he can do so without getting lost in space. If he feels like relaxing, or romping around, there is another area for it all in the same room. The furniture is sturdily built, functional, colorful and stimulating. Each cottage, depending on the age of the child and the psychopathology, has entirely different space arrangements. The cottage for the adolescent boys and girls provides an informal atmosphere conducive to comfortable, stimulating, social living, appropriate to the age of the patients as well as to the staff. The change in behavior of the children on all levels has been dramatic following the rearrangement of space. In recent years we have had no more destruction on a cottage with forty children than in any normal home with six or more children, and probably far less than in any well-run boarding school.

The Satellite Treatment Home concept which was dealt with in the first part of this presentation owes its origin and development to the need of the disturbed child under treatment for a steady, reliable and continuous relationship with parenting figures, hopefully, who receive training in child care and treatment. It owes its development, also, to the need of the disturbed child for normalization of his living conditions which can best be done in an average, expectable home environment, in an average neighborhood, in their own communities. The concept of the Satellite Treatment Home embodies other features which can be used not only for the promotion of the well-being of the child while under treatment, but can also be used to improve the standards of his treatment. One of these features is the special arrangement of the physical space surrounding the child and staff. For instance, large wards where sixty, forty, or even twenty children live deprive these children not only of their privacy and opportunity to intimately relate with each other and with staff, but it also deprives them of their self-esteem and human dignity. Such large living quarters, Grand Central Station-like, often counteract the therapeutic efforts of the personnel assigned to the care and treatment of these children, entirely apart from the isolation of these children from community living, and entirely apart from the deprivation of the crucially important, steady and continuous parenting relationship with staff members.

It must be conceded that, at the present time, there are large numbers of severely psychotic children, deaf and blind, retarded and other developmentally handicapped children who live under a variety of conditions, including "back wards" to which several speakers referred in the conference, and who, for a variety of very realistic considerations, could not be moved, without providing intermediate stages, to the Satellite Treatment Homes in the community. One should, therefore, consider for the transition period developing intermediate facilities between the back wards where children now linger on and the Satellite Treatment Home in the community where they should be heading. In planning for these intermediate steps the structure of the physical environment of the Satellite Home could be used. Four- or five-bedroom cottages could be built, or existing employees' homes could be used within an institutional setting within the area of the present state hospital for the placement of the children now living in back wards. Or clusters of such homes could be built within the community or very close to a major community comprising a region of several counties for the care and treatment of these children. Such clusters of homes will require a day treatment center for schooling and socialization of these children. One could visualize then that the children from the back wards would move into such Satellite Homes within the confines of an institution as the first step towards normalizing their lives; and as a second step these children could move to a cluster of Satellite Homes located within the community; and the final step could be to integrate them into either Satellite Treatment Homes within a normal neighborhood in the community, into foster homes, or into their own families. A number of children may not be able to progress for some years beyond the first stage of the Satellite Home within an institution or within a cluster of Satellite Homes in the community. B[illegible] the chances of their rehabilitation in individual family homes is far greater than if they would remain on a back ward, or even a "front ward", not to mention the many other gains for these children by providing them with dignified living conditions to which all of them are entitled. For the long term, whatever cost may be involved in such arrangement of their living conditions will be far outweighed by the advantages gained for these children and for society. Much of this could be a practical reality by 1980 if funding could be obtained for implementation of such a plan. This could be done in the form of a research project which could compare and evaluate the various placements which such a plan envisions.

The Human Environment

However important the space area is for the care, treatment, and education of developmentally handicapped children, it is only their environmental background or structure in which treatment takes place. The concept of structures carries over into treatment. Just as organization of physical space supports the developmentally handicapped child in his body ego, so the therapist's or educator's own ego provides the ego transfusion for the mentally or otherwise handicapped child to function either in a homelike environment or in a structured educational setting. It is not enough to surround these young, developmentally handicapped children with "technicians" who have been trained to acquire certain techniques for remediation of specific deficiencies in these children: such as sign language for the deaf, sensorimotor skills for the blind and physically handicapped, special education for the emotionally disturbed and mentally retarded, or speech and language for the aphasiac child. What is urgently needed are specially selected and specially trained people to deal with the whole child, the normal child, the emotionally and mentally disordered child, the sensorily deprived and physically handicapped child. In the various training programs for the deaf-blind, for the great variety of developmentally handicapped children, it is often forgotten that the child is a total being who not only requires specialists for special needs but also, and primarily, requires generalists for his total needs.

It must not be forgotten that the child is not a small adult, a finished product as it were. He is rather in the process of growing, changing and becoming. His needs are not met by teaching him or her certain skills. The child requires having his emotional needs met, his self-esteem developed, his identity established. Because of the necessity to possess this special ability to deal with developmentally handicapped children, treatment cannot be done by people who have been trained to deal with emotionally or otherwise handicapped such as blind and deaf adults. Such people first have to unlearn certain practices and approaches which, although effective with adults, may have an adverse reaction when applied to children. They have to learn new ways and techniques. And although this is not impossible, as numbers of successfully retrained personnel show, it is a very inefficient way of building a cadre of experts who are capable of clinically managing developmentally handicapped such as mentally disturbed and delinquent children. Also, because of their specialized skills in dealing with particular problems of disturbed children, professionals such as child psychiatrists, special education teachers, play therapists, speech therapists, child psychologists, et cetera, have too many demands made upon their expertise to be able to provide the child with the type of continuing integrated attention which is necessary to deal with him effectively and successfully.

In addition to specificity of training, most of the existing programs appear to be university based. The disadvantage of this is that traditionally the academic aspects are the primary function of the program; and the clinical experience which the trainees receive is a separate, fragmented, and often not necessarily related entity. What is mandatory for the training of competent child care personnel as proposed for the present Child Mental Health Specialist is a reversal of this customary approach. The trainee should receive clinical experience from the very first day that he is enrolled in the program. First, he receives the "gut" learning, and only after the impact of the encountered pathologies does the trainee receive a review of the academics which are related with these pathological behaviors. As a result, there is no division or fragmentation of academic and field approach, and the trainee is intimately able to understand and interpret the symbolic meaning of the child's behavior.

The training of the new professional, the Child Mental Health Specialist, must also involve learning ways and means of dealing with normal children. Trained personnel must know and have experience with the normal development of children. It is vitally important that emotionally disturbed children, retarded children, deaf and blind children, do not get a label attached to them such as psychotic, delinquent, retarded. A handicapped child should not be viewed as the appendage to his handicap or to his illness as it is so often done in institutional settings. In the treatment of any handicapped child—mentally disordered, or retarded, or blind— the normal behavior needs to be emphasized and the psychotic, the abnormal and pathological behavior needs to be de-emphasized. It has been our experience that the child responds maximally only to a capable, motivated and sensitive person when he is perceived, treated and interacted with basically as another normal person who needs help.

The new professional is being specifically trained to take total integrated care of the handicapped child on a twenty-four hour basis, if need be. He is being trained by members of an interdisciplintary team in order to give him a broad, general training in a variety of fields. The scope of the program which we have established for Child Mental Health Specialists is broadly based in that it proposes to train people capable of work and assuming leadership in a great variety of areas and not necessarily only in special specific areas as working in day care centers or teaching disturbed preschool children. In addition, it provides the Child Mental Health Specialist with a number of different options for additional personal and educational development. Our training philosophy has envisioned rapid changes in our social structure, in our value system, and in our treatment philosophy. In developing our training program, it has become, therefore, necessary to train contemporary personnel in such a fashion that their skills are sufficiently versatile and flexible so that they do not become obsolete in ten or twenty years. Care should be taken that contemporary trainees are able to meet changing needs. Parochial training should be avoided because this may lead to obsolescence. For instance, psychiatric technicians who were traditionally trained in custodial care of patients have not been adequately trained for the changing focus of treatment to community outpatient centers. They function primarily in a hospital-type setting. As a result, the change in treatment focus has jeopardized their continuing employment. Contemporary training of child care personnel, therefore, should insure that such people are able to adopt a variety of roles in a variety of employment situations. They should be able to apply their talents wherever they are needed in whatever mental health situation, whether it is a hospital, a community mental health center, a day care center, a special education class in a school situation, a foster home, or other situations. A "generalist" type of training will give the added advantage of making it possible to provide a fully integrated treatment and prevention service rather than the customary fragmented and often disjointed approach.

Thus, when the critical work requirements of dealing effectively and successfully with emotionally disturbed and otherwise developmentally handicapped children are analyzed, we find that a Child Mental Health Specialist should be able to deal with the *total* child and his many-faceted needs. He should be able to respond, interact, and relate to the child with the empathy and sensitivity of an ideal parent, some of the information and knowledge of a special teacher, and with the basic tools and skills of a child therapist. He must understand the symbolic meaning of the children's behavior as expressed in their daily interaction with grown-ups and respond to these symbolic communications in a manner which will lead to a successful restructuring of the child's emotional life. In addition, it is essential that the Child Mental Health Specialist acquire the ability to deal with the tremendous frustrations which result from spending many hours daily with mentally ill, deaf-blind, or other handicapped children in intimate conditions.

The Child Mental Health Specialist, therefore, should be capable of providing the children with a personal genuineness, an ability for intellectual and affective sympathy, a warm unconditional positive regard even while restructuring certain of the child's behaviors, an ability to communicate, to discriminate, to handle crises, and an ability to gain from learning experiences. The prospective Child Mental Health Specialist must be trained to be a warm, sensitive and positive responder and interactor, not only because he will handle daily behavioral crises, but also because he should be prepared to handle special educational needs of the child, the supervision of paraprofessionals, the prevention of emotional disorganization of families of mentally ill children in the community, as well as be able to provide leadership in the general prevention of emotional disturbance and delinquency in children in the community. The Child Mental Health Specialist must be a person capable of working in the area of prevention in addition to working with children with minimal pathology or with very severely disturbed children.

The breadth and depth of training, therefore, prepares a Child Mental Health Specialist to manage children from birth through adolescence and to deal sensitively and with empathy with the total child and his many different needs.

The Emotional Support System

When a seriously disturbed child is sent to a state mental hospital, he is sent there not only to receive treatment. More often than not, he is sent there to be away from his own home or his foster home. The strain and stress of caring for a psychotic child in one's own home is more than the average family can cope with. Very often such a child could be kept in his own home if the necessary support system were available to the family, such as a day treatment center where the youngster could get treatment or special education, and where he could learn how to socialize with other children, or where he will have an opportunity to become involved in other ego-building activities. A disturbed child could often be kept home if a trained person could be available to the family, particularly to the mother, to assist her in the management of the child during certain hours of a day, and/or to advise and guide the parents in management of the youngster. In the absence of such support, the child is sent to a state hospital or to another institution for his emotional survival as well as for the emotional survival of the family.

The state hospital or other institution where a child is sent is expected to provide a support system to the child in the form of a therapeutic milieu. By therapeutic milieu we mean the use of the total environment for the treatment of the child. The most important part of such a milieu is the human environment which can provide a structure within which the disturbed child can learn to cope both with the reality of his external environment and with his inner turmoil. Personnel who are assigned to work with these children, day in and day out, and who have to deal with the many frustrations resulting from their management, need a support system of their own for their emotional survival. Such support can be provided by consultants, by continuous training, by providing them with opportunities towards their self-development and self-awareness, and by helping them develop the myriad of coping mechanisms which becomes available to them by mobilizing their own inner resources.

Emotional support of those who work with disturbed children is as important for the professional growth of individual staff members as it is for the child's growth and development through treatment. Psychotic children, through their behavior, provoke in all of us feelings and reactions which may run the entire gamut of helplessness, fear, anger, disgust, which the individual staff member has to learn to integrate without leading to acting-out behavior towards the child and towards other staff members. He or she has to learn how to cope with frustrating feelings which are inevitable without reacting by withdrawing from the child or indulging in other pathological defenses. Individual staff members need, at all times, access to readily available consultation services to become aware of their deeply felt, aroused feelings. They need emotional support in helping them to integrate these feelings leading to personal and professional growth. Unfortunately, such consultation services are difficult to provide in large institutional settings; and the needed support is difficult to obtain. The result is subtle acting-out behavior towards the child and towards other staff members. Instead of having a therapeutic milieu, we often have a milieu full of tension, full of resentment on different levels of line and supervisory personnel. To establish an effective therapeutic milieu on a ward with forty or even twenty children and a correspondingly adequate staff would require heroic efforts and would be staggeringly expensive. The importance of providing emotional support to people who work with psychotic children as a sine qua non was driven home in a dramatic fashion when we opened our first and subsequent Satellite Homes for the treatment of such children in the community. None of the couples who staffed the four Satellite Homes over the past four years would have survived as parenting figures the first few weeks without the emotional support and the consultation services which were available to all of them regularly, and particularly during crises periods and in emergency situations. We not only became aware of the strains and stresses which parenting figures have to endure in caring for four psychotic children twenty-four hours a day, seven days a week, but we also found out that the parenting figures have learned to cope with the many daily frustrations when they had ready access to such emotional support and consultation. Over a period of time we could observe not only how the children change in their behavior, how they developed and matured, but we could also observe the personal and professional growth of their parenting figures.

Prevention

Prevention in the mental health field is a much more complex task and more difficult to accomplish than it is in medicine. When we talk about prevention, we usually refer to primary prevention, i.e., to prevent the spreading of an illness at the source by taking public health measures concerning food, water, sewage, to prevent the spread of typhoid fever, or by vaccination against smallpox or diphtheria to prevent their occurrence in entire populations. An example of primary prevention of deafness and blindness in newborn children resulting from rubella would be the vaccination against rubella of future mothers. Similarly, we can prevent certain known hereditary mental illness or mental retardation by genetic counseling either before marriage or before conception.

In talking about prevention in mental illness, and particularly in children, we often refer to secondary and tertiary prevention as well. By that, we mean to limit an existing handicap to a circumscribed area of the personality functioning and to prevent the handicap from affecting other aspects of the personality development. In the context of our discussion of prevention dealing with newborn deaf and blind children, we refer to secondary prevention. Thus, at any stage of a handicapped child's development, we may practice prevention by trying to help the child develop towards becoming a well-integrated person in all areas which are free from the handicap. Also, by developing compensatory mechanisms and skills, we try to help the child to learn to live with his handicap. Particularly in newborn and very young children, we are trying to provide the child with an understanding and affectionate environment to help him experience and master all stages of development leading to attachment to his parents and siblings, and to provide him with an environment in which he will learn how to cope with the daily vicissitudes of growing up as a normal child will learn in the process of growing up. The earlier prevention is practiced, the more effective and more enduring and less costly it will be to the family and to society. Infancy and early childhood is a time when most can be accomplished with the least time, effort and cost. This applies to all preventive measures, but it would particularly apply to deaf and blind children.

Present-day research and knowledge in child development does not provide us with knowledge about analogous pathways in the child's developmental stages to overcome specific handicaps such as in organically damaged children, autistic children, and deaf and blind children. We know from clinical observation and experience that any congenital handicap would limit the child's developmental capacity because it will adversely affect the feedback of the people in his environment. It is this feedback from the environment which may cripple the child's personality and future functioning as an adult. Fraiberg (1) has demonstrated that blind babies may escape the arrest of the growth pattern, the passivity, the lack of motoric development and limited relatedness to people which she found in many blind infants. In a detailed study of eight chidren who were born blind, whom she and her staff had an opportunity to observe from time of birth, or shortly thereafter, for a period of several years, she reported that much can be done during this crucial period of infancy to prevent personality distortions. She stated that not blindness alone, but tactile and auditory insufficiency in the early months will prevent the baby from making the vital attachment to his mother and to the human world. She reported that each of the blind children in a longitudinal study has "shown a phase-by-phase human attachment during the first year paralleling in significant ways that of sighted babies." She reported that the blind babies followed in all essential respects that of the development of the sighted child. Seven out of eight children followed language norms for sighted children. These favorable results in the blind babies were obtained because the mothers of these babies could, under guidance and with emotional support, create favorable conditions for the development of these babies through physical closeness by holding, through proper stimulation, through play, and by placing the baby in the center of family activity during waking hours. She concludes her study by noting:

> *The adaptive problems appeared in each of the children studied in a range of human environment that permitted some assessment of qualitative factors in mothering. It is not blindness alone that imperils a child's development, but the absence of vision as an organizer of experience, the absence of vision as a facilitator of gross motor achievement and prehension, the absence of vision in constructing a stable mental representation, and the obstacle to finding motor pathway for aggression that can lead to defense and neutralization of aggression in the service of the ego.*

Because the blind child is far more vulnerable than the normal child, his needs for qualitatively better emotional and sensory motor stimuli are greater than those of the average normal child during the first two or three years of life. It is during this period when an adequate emotional support system for the child and family can have a decisive influence on the child's future development. The Child Mental Health Specialist with some training in the management of the deaf-blind child could become a very effective component of the emotional support system by being available several hours daily to the young infant and by providing emotional support and guidance to the child's parents and family during the first years following the birth of the child. This could prevent personality constriction and costly treatment in the future. Providing the deaf-blind infant with a better than average expectable environment with the most favorable conditions for personality development would be far less costly than lifelong institutionalization.

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1. Fraiberg, Selma. Parallel and Divergent Patterns in Blind and Sighted Infants. The Psychoanalytic Study of the Child, Vol. XXIII, 264:300, 1968.